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# Informal Care in England





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# INFORMAL CARE IN ENGLAND

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*King's* **Fund**

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# Summary

The provision of long-term care to older people relies very heavily on the contribution of informal carers. This paper looks at the provision and hidden costs of informal care, and factors such as changing demographics, that will influence the future availability of informal care.

- It is estimated that, in 2000, there were around 5.8 million carers in England, of whom between 3.4 and 4 million were providing care to those aged 65 and over.
- More than a fifth of carers who are living with the care recipient provide care for 100 or more hours a week.
- Informal carers provide personal care and monitor medication, but they devote most time to practical care tasks, such as shopping and laundry. Large numbers of carers also see a key role as providing company and ‘keeping an eye’ on the older person, particularly if cognitively impaired.
- The older generation supplies a disproportionate amount of care. In 2000, 16 per cent of people over the age of 65 were providing some form of care, and this age group made up 28 per cent of carers providing 20 hours or more care each week.
- Women tend to have heavier care commitments, although the gender division with regard to caring has become less weighted in recent years.
- Other factors that impact on the propensity to provide care include economic status, level of education, location and ethnicity.
- Carer support and information services do exist, but are currently received by only a minority of carers.
- Estimation of the true gross financial cost of informal care to both society and the individual is difficult. An accurate figure would need to take account of reduced earnings from employment, the consequent loss to the Exchequer, the long-term impact of reduced pension contributions and the cost of carer support services. There are also indirect or non-financial costs of caring, such as social exclusion, erosion of personal relationships and adverse effects on health (which then present a cost to the NHS).
- Availability of informal care may well not keep pace with increases in care needs in the future. Assuming current patterns of care, the Personal Social Services Research Unit (PSSRU) model suggests that, from 2003 to 2026, the ‘demand’ for informal care will increase by around 45 per cent.
- Various trends affect availability of informal care. There has been a significant decline in co-residence between adults and elderly parents, and an increase in one-person households, both of which point to lower availability of informal care. In addition, people who might currently be prepared to care for those in need in certain circumstances may not be so willing in future.
- Possible approaches to securing future supply of informal care and supporting carers are examined for development based on their varying levels of effectiveness and cost-effectiveness.

Informal care will continue to provide a very significant input to social care, even if increases in availability fall short of future demand. Greater carer support is needed to relieve some of the pressure of care, because the costs of increasing formal care to meet a significant reduction in informal care would be prohibitively high.

# Introduction

According to official sources, carers are defined as ‘people who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness’ (Department of Health 2005a). This ‘looking after’ can be in the shape of active support, supervision or social interaction, all of which are provided by informal carers.

Although the term ‘informal carers’ is frequently used, many object to this, arguing that the caring service provided by ‘informal’ carers is formal in everything but the receipt of pay, and many carers feel that they have had little choice in taking on their role. This might suggest that ‘unpaid’ care is thus a more apt title. However, there are also potential problems with this term, with its use possibly leading to confusion. For example, it is possible for informal carers actually to receive some form of financial remuneration through direct payments.

For the purposes of this paper (and the Wanless Review), the term ‘informal care’ is used and adopts the definition used by the General Household Survey (GHS) – that is, support (looking after or other ‘special help’) provided to sick, disabled or elderly people aged over 65, in a non-professional capacity. This definition is considered to be the least problematic, but is used with the caveat that the term ‘informal care’ can be a misleading term for the magnitude of the task that it describes and the dedication and scale of commitment of the individuals who perform it.

A further consideration is whether contributing towards the financial burden of formal care is to be considered as caring in the same way as directly providing care to an individual. This is a question of significance, but more for the sake of information, statistical collection and policy direction than for the physical impact on the carers themselves. There is no consensus on this issue. For the purposes of this paper, the term ‘informal care’ includes only those who directly provide care to the recipient rather than simply paying for formal care.

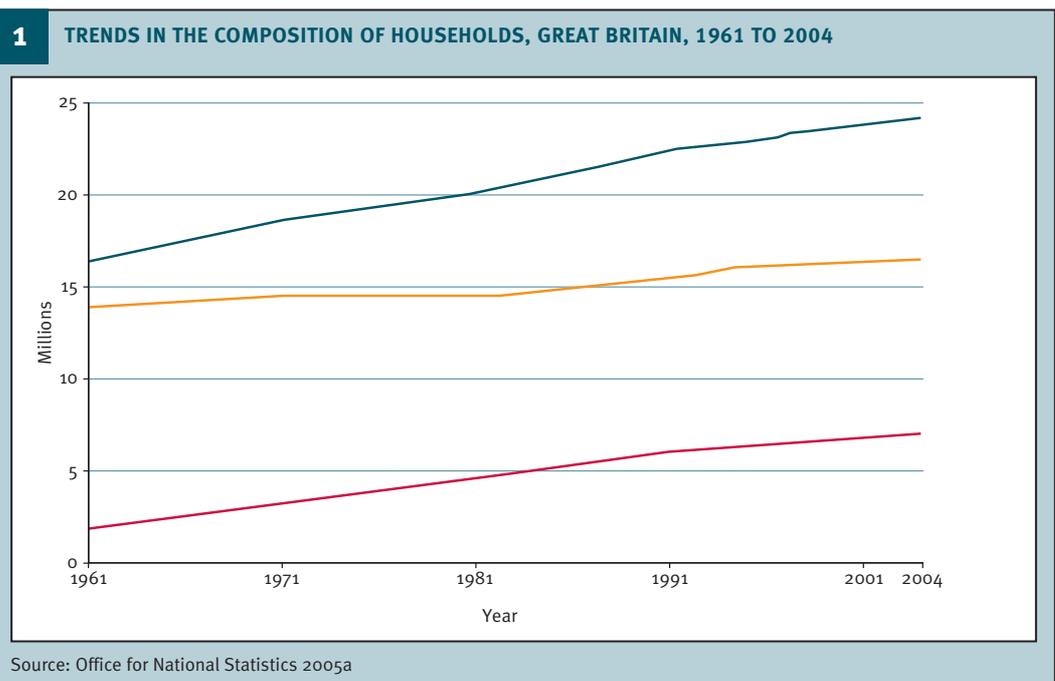
The Wanless Review looks specifically at the carers of people aged over 65, but also at the care provided *by* individuals who are aged 65 or over. In many cases these two groups are very closely associated.

# Current position

## Carer inputs

### Numbers

In recent years, there has been a small (but not steady) increase in the prevalence of caring in Britain. Households with carers and carers in the population have stayed between 16–21 per cent and 11–16 per cent, respectively, between 1985 and 2000 (Maher and Green 2002). The situation of people being cared for is changing, however. There has, for example, been a consistent increase in the number of one-person households in England and Wales (Office for National Statistics (ONS) 2005a). In 2004, one-person households made up 29 per cent of all those in England and Wales, whereas people of pension age were twice as likely to be living alone than they were in 1961 (the figure for older people living alone has now risen to 7 million). This is alongside a fairly consistent increase in households as such (although this has levelled off slightly in recent years – see Figure 1 below) (ONS 2005a). When taken together, these trends in prevalence of caring in households and household numbers and occupancy have significant implications for the amount of care needed in the future.



**TABLE 1: ESTIMATED NUMBER OF CARERS<sup>1</sup> IN GREAT BRITAIN, BY COUNTRY, 2000**

Country	Informal carers in Great Britain	
	Percentage of GB total	Derived number (millions) <sup>2</sup>
England <sup>3</sup>	86	5.767
Wales	5	0.335
Scotland	9	0.604
<b>Total</b>	<b>100</b>	<b>6.706</b>

Source: Calculated using figures from Maher and Green 2002

<sup>1</sup> Includes those caring for all age groups.

<sup>2</sup> Calculated through application of percentages derived from Maher and Green 2002 to 6.706 million (total number of carers in Great Britain).

<sup>3</sup> Calculated from Carers 2000 figures.

**TABLE 2: ESTIMATED NUMBER OF CARERS, BY AGE OF CARE RECIPIENT AND LIVING ARRANGEMENT, ENGLAND, 2000**

Age of care recipient	Carers with main person cared for		Percentage of total carer population	Derived number (millions) <sup>1</sup>
	In the same household (%)	In another household (%)		
Under 65	56	17	30	2.669
65–74	18	18	18	1.038
75–84	16	41	33	1.903
85+	9	24	19	1.078
<b>Total 65+</b>	<b>43</b>	<b>83</b>	<b>70</b>	<b>4.037</b>

Source: Calculated using figures from Maher and Green 2002

<sup>1</sup> Calculated through application of percentages derived from Maher and Green 2002 to 6.706 million (total number of carers in Great Britain).

Data vary according to the source that is used and the definitions and inclusions within this (as is the case in formal care). Analysis of the 2001 Census gives a figure of 4.9 million people providing some care in England, which would imply around 3.4 million people caring for those aged over 65. According to *Carers 2000*, however (Maher and Green 2002), in 2000 there were approximately 6.7 million carers in Britain. An estimated 86 per cent of these carers were in England (5.8 million), whereas 70 per cent of care recipients looked after by these carers were aged over 65. Calculations using *Carers 2000* therefore indicate a caring population for people aged over 65 in England of around 4 million people<sup>1</sup> (Tables 1 and 2 above give details for these numbers and their calculation). This paper (and the main report on the Wanless Review (Wanless 2006)) use data from *Carers 2000* (Maher and Green 2002).<sup>2</sup>

### Hours

The time devoted to caring varies. Although a large majority of carers spend less than 20 hours a week on caring responsibilities, a small but significant minority spends at least 50

**TABLE 3: CARERS OF PEOPLE AGED 65+, BY NUMBER OF HOURS PER WEEK SPENT CARING AND LIVING ARRANGEMENT, 2000**

Number of hours per week spent caring for main person cared for	Percentage of carers of people aged 65+		
	Person cared for in carer's household	Person cared for in another household	All
0-19	33.4	89.0	78.0
20-34	14.3	5.7	7.3
35-49	9.8	2.0	3.5
50-99	11.8	0.8	2.9
100 or more	20.7	0.4	4.3
Varies, 20 or less	2.2	0.7	1.1
Varies, 20 or more	6.4	0.5	1.6
Other	1.4	1.0	1.3

Source: Based on unpublished analysis of the General Household Survey 2001, prepared for Review by Office for National Statistics

hours a week caring, and some of these are committed for over 100 hours per week. Table 3 above gives details of the hours spent in caring for people aged over 65.

Hours vary significantly with various factors and the circumstances of both the carer and the care recipient. Together with the factors that impact on the provision of care itself (discussed below), there are two main factors that impact specifically on the hours spent caring:

- residential status: carers living with the person for whom they care are more likely to spend more hours looking after the care recipient; in 2000, more than 20 per cent of carers living in the same household cared for 100 or more hours per week. Those living in another household are very unlikely to care for 50 or more hours per week, with the majority of carers in this group caring for under 20 hours per week (see Table 3 above).
- the care episode: research suggests that the time spent caring does not necessarily increase over time, but that there are 'substantive differences in the intensity and scope of caregiving between short, transitory spells and longer episodes', those carers who provide more intense care are likely to do so from the beginning and for longer durations of time (Hirst 2002).

## Nature of care

The tasks performed by informal carers are often very similar to those performed by formal carers, but vary in the time devoted to different types of support. Tasks such as personal care and giving medication make up the majority of formal carers' work but are provided by smaller proportions of informal carers. For example, personal care, one of the main tasks provided by formal carers, is provided by less than a quarter of informal carers (Maher and Green 2002). Tasks such as meal preparation, shopping, laundry and helping with mobility form the core of tasks performed by the majority of informal carers (Maher and Green 2002; ONS 2004i). Large numbers of carers also see a key role in providing company and 'keeping an eye' on the person generally (what some describe as 'supervision'). This task is particularly important when the cared-for person is cognitively impaired or confused.

**TABLE 4: TYPES OF HELP GIVEN TO MAIN CARE RECIPIENT, BY LIVING ARRANGEMENT, GREAT BRITAIN, 2000**

Help given	Carers with main person cared for		Percentage of total carer population
	In the same household (%)	In another household (%)	
Personal care (eg washing)	51	15	26
Giving medication	44	11	22
Physical help (eg with walking)	57	25	35
Paperwork or financial matters	41	38	39
Other practical help	69	73	71
Keeping company	49	58	55
Taking out	49	53	52
Keeping an eye on person cared for	62	59	60
<b>Weighted base (thousands) = 100%</b>	<b>2,164</b>	<b>4,537</b>	<b>6,701</b>
<b>Unweighted sample</b>	<b>742</b>	<b>1568</b>	<b>2,310</b>

Source: Maher and Green 2002

Once again, the household status of carers, that is whether they live with the care recipients or not, has an impact on the type of care provided. Those living in the same household are much more likely to help with personal and physical tasks than those caring for someone in another private household (Hirst 2001; Maher and Green 2002). Table 4 above gives more detail on the types of help provided, and the relationship with living circumstances.

## Factors affecting the provision of informal care

Categorising the provision of informal care is important, not least because disaggregating care allows more accuracy when attempting to predict future numbers. Many personal and circumstantial factors impact on the likelihood of a person providing care, as follows.

### *Relational status*

The most significant sources of informal care for older people are their adult children (and children-in-law – filial carers) and spouses (or partners). Table 5 overleaf shows the estimated numbers of carers for older people in England according to their relationship with the care recipient. These have been derived from figures from *Carers 2000* applied to the carer population for England (Maher and Green 2002). It is important to note that the number of carers tends to be higher than the number of care recipients. In particular, many older people have more than one child providing care. It is not possible, from the data available, to derive estimates of numbers caring for older people specifically by relational status. As indicated above, however, *Carers 2000* suggests that 70 per cent of carers care for people aged over 65. This could also apply to these figures.<sup>3</sup>

**TABLE 5: NUMBER OF CARERS, BY RELATIONSHIP WITH CARE RECIPIENT, 2000**

Relationship of carer to care recipient	All carers		
	Great Britain <sup>1</sup> (%) <sup>2</sup>	Great Britain (millions) <sup>3</sup>	England <sup>4</sup> (millions)
Spouse	18	1.2	1.0
Child/child-in-law	52	3.5	3.0
Friend/neighbour	21	1.4	1.2
Other	30	2.0	1.7
Total		8.1	7.0

<sup>1</sup> Based on figures in Maher and Green 2002.

<sup>2</sup> Percentages add to more than 100 because some carers were looking after more than one person and are therefore counted more than once in these figures.

<sup>3</sup> Estimate, Wanless Review.

<sup>4</sup> 86 per cent of total for Great Britain.

### **Marital status**

Married or co-habiting adults appear to be more likely to be carers than those who are single or previously married (19 per cent compared with 10 per cent and 12 per cent) (Maher and Green 2002). This is also significantly linked to gender and age trends, and is obviously very closely related to relational status (*see above*) and household status (*see below*).

### **Household status**

As discussed above, the residence of the carer in relation to the care recipient has a significant impact on the time spent caring. Those who live in the same household tend to be involved in care-giving for a greater amount of time. For example, some 63 per cent of those in the same household spend 20 hours or more on caring each week, compared with 11 per cent of those carers living in another household (Maher and Green 2002).

The household status of the carer to the care recipient also has an impact on the likelihood of being a main or subsidiary carer. Those who live in the same household are twice as likely to be the main carer as those looking after someone who lives elsewhere (Maher and Green 2002).

### **Age**

The burden of care is shouldered disproportionately by the older generation, both in the proportion caring and in the hours of care provided. In 2000, 16 per cent of people aged over 65 were providing some form of care, equating to 28 per cent of all carers providing 20 hours or more care each week. This proportion had increased between 1985 and 2000 (shown in Table 6 opposite), but the data are insufficiently detailed to indicate whether this is a consistent trend. Carers aged over 65 are also more likely to spend 50 hours or more caring per week; in 2000 some 37 per cent of carers aged over 65 were caring for 50 hours or more per week for a care recipient with whom they lived, against an average of 31 per cent for 30 to 64 year olds who were co-resident with the recipient.

**TABLE 6: PERCENTAGE OF PEOPLE AGED 65+ WHO ARE CARERS, BY GENDER, 1985 TO 2000**

Gender	Percentage of people aged 65+ who are carers			
	1985	1990	1995	2000
Men	14	14	14	18
Women	12	13	11	15
<b>Total</b>	<b>13</b>	<b>13</b>	<b>13</b>	<b>16</b>

Source: Based on data from Maher and Green 2002

Research indicates that the probability of becoming a carer increases with age, with probability notably being high for co-resident care as people age (Hirst 2002). It is noteworthy that the probability of women becoming carers remains consistently higher than for men in all circumstances, apart from for co-resident caring after the age of 75, when men become more likely to start looking after someone in the household. This is illustrated in Figures 2 and 3 (overleaf).

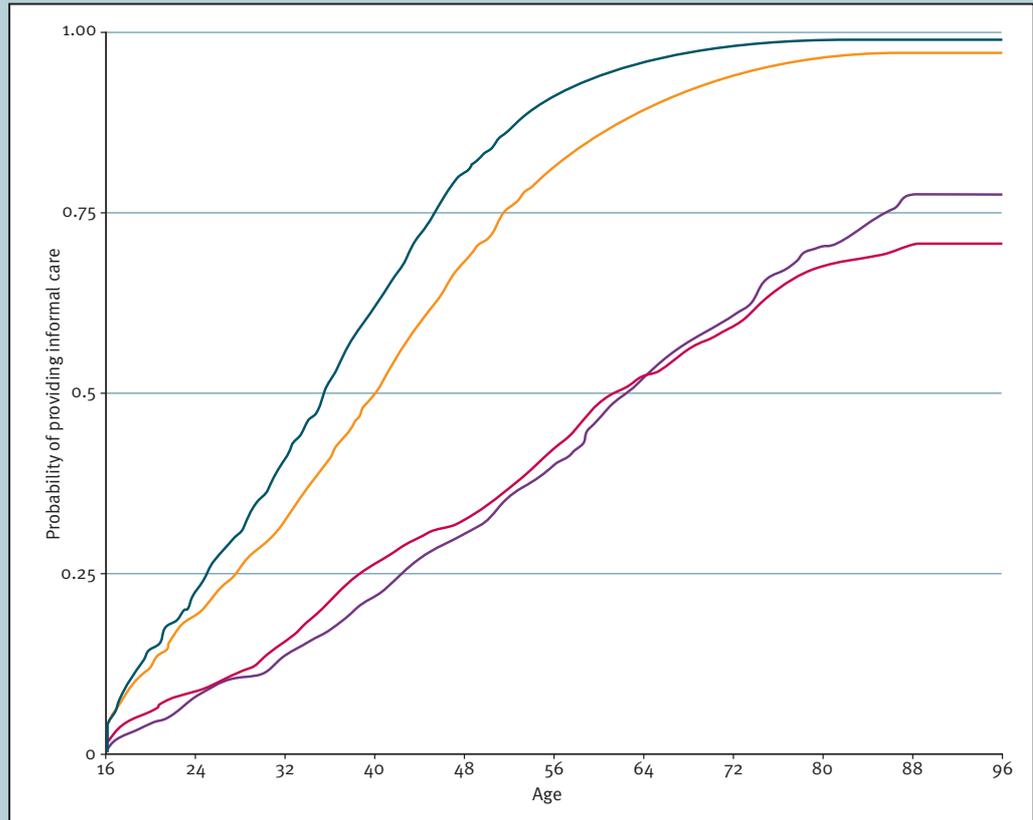
### **Gender**

The role of caring has traditionally been performed by women. In recent years, the gender division in care provision has become less weighted, but care still tends to be provided disproportionately by women. Census data show that, in 2001, in the population as a whole a greater proportion of women than men were carers (ONS 2004d). Women also tend to have heavier commitments, with 11 per cent of women compared with 7 per cent of men being main carers, and 5 per cent of women compared with 3 per cent of men spending 20 hours a week or more on caring tasks (Maher and Green 2002).

As illustrated in Figures 2 and 3 (see overleaf), there is, as might be expected, a correlation between gender and other influences on the propensity to care. Figures 2 and 3 highlight the influence of gender on both the probability of caring and the number of hours spent caring, and also illustrate that the age and gender of the carer are inextricably linked to the propensity to care, and to each other. These relationships are also found in other data sources. Data from the 2001 Census (see Table 7 below) show that where carers co-reside with the care recipient, women have a higher probability of providing both care and more than 50 hours of care per week, up until the age of 75. In the later stages of life, however, a larger proportion of men provide both care and more than 50 hours of care per week. It is estimated that, in 2001 in the UK, there were 179,000 male carers and 169,000 female carers aged 75 and over – representing 12 per cent of men within this age group and 7 per cent of women (ONS 2004e). This gives a figure for England of 154,000 and 145,340 respectively.

Both the impact of gender on propensity to care and the interrelationship of factors are also illustrated by data from the English Longitudinal Study of Ageing (ELSA) data. Figures 4 and 5 show the way in which relational status, gender and age interact, and the impact that these combined factors has on the propensity to care.

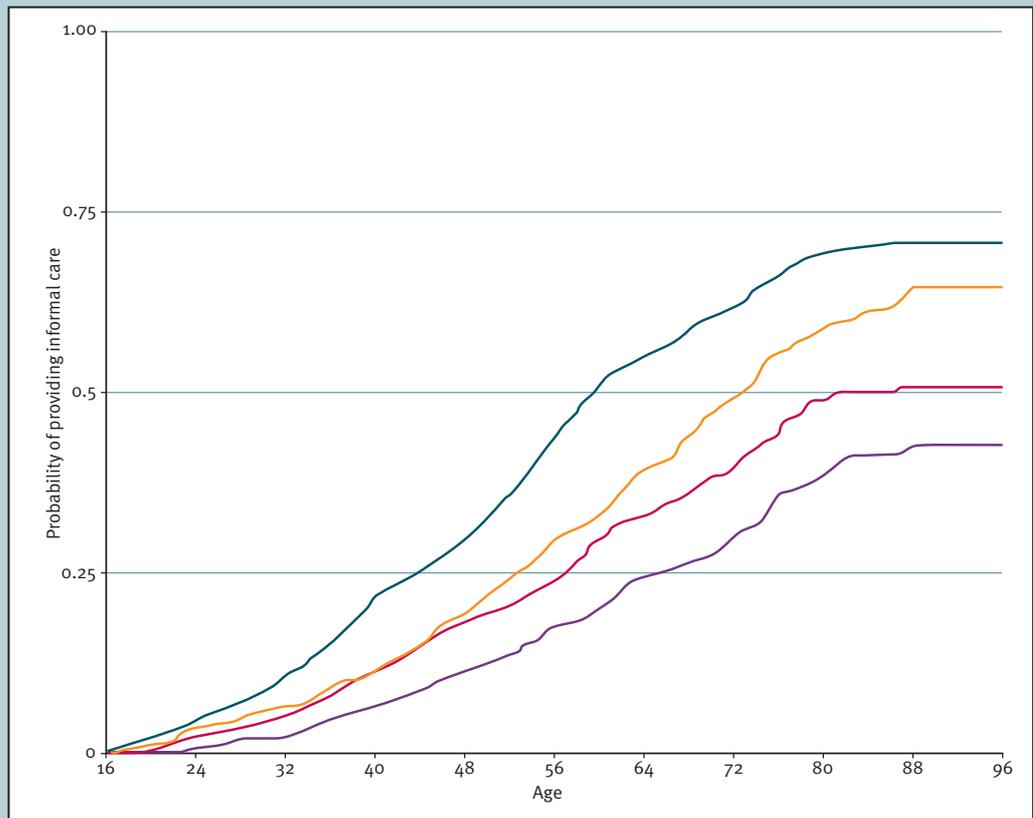
**2 CUMULATIVE PROBABILITY OF PEOPLE PROVIDING INFORMAL CARE, BY AGE, GENDER AND LIVING ARRANGEMENT, GREAT BRITAIN**



Source: Hirst 2002

- KEY**
- Women caring for person outside home
  - Men caring for person outside home
  - Women caring for person inside home
  - Men caring for person inside home

**3 CUMULATIVE PROBABILITY OF PEOPLE PROVIDING INFORMAL CARE, BY AGE, GENDER AND NUMBER OF HOURS SPENT CARING PER WEEK, GREAT BRITAIN**



Source: Hirst 2002

- KEY**
- Women caring 20+ hours
  - Men caring 20+ hours
  - Women caring 50+ hours
  - Men caring 50+ hours

**TABLE 7: CARERS\* WHO LIVE IN HOUSEHOLD OF CARE RECIPIENT, BY AGE AND GENDER, UNITED KINGDOM, 2001**

Age of carer	Number of carers* (thousands)		Percentage of carers providing 50+ hours of care a week	
	Men	Women	Men	Women
45-54	613	896	15	17
55-64	519	697	19	23
65-74	319	370	31	34
75-84	155	149	44	44
85+	24	20	54	47
<b>Total aged 45+</b>	<b>2,460</b>	<b>3,399</b>	<b>20</b>	<b>22</b>

Source: Based on figures from Office for National Statistics Census 2001, General Register Office for Scotland Census 2001, Northern Ireland Statistics and Research Agency Census 2001, cited in Office for National Statistics 2004f.  
\* Those providing unpaid care in the form of looking after or giving help or support to family members, neighbours or relatives.

There are several reasons for the disproportionate involvement of women in providing care (with the exception of care in later life, as discussed above). The main factor appears to be the expectation that performing caring responsibilities is a traditional female role. This is illustrated, for example, by the British Social Attitudes' Survey (National Centre for Social Research), which shows, on examination of the division of household tasks, that there is a strong tendency for women in a relationship to undertake the caring role for other family members (ONS 2004a) (see Table 8 below).

In addition to this, there is the continued discrepancy in levels of workforce participation between men and women. Although there has been a rise in employment among women, they are still less likely to be economically active or in part-time employment (ONS 2004b, 2004c). This is illustrated in Table 9 overleaf. It not clear whether lower levels of economic activity among women are the result of caring responsibilities or whether the greater 'availability' of women to care contributes to the higher caring prevalence among women. It is likely that a combination of the two factors is involved.

**TABLE 8: DISTRIBUTION OF RESPONSIBILITY FOR HOUSEHOLD TASK OF LOOKING AFTER SICK FAMILY MEMBERS, BY GENDER, 2002**

Gender of respondent	Responses to question: 'In your household, who looks after sick family members?'						
	Always me (%)	Usually me (%)	About equal or both together (%)	Usually spouse or partner (%)	Always spouse or partner (%)	Done by a third person (%)	Total (%)
Men	2	4	46	31	15	2	100
Women	29	33	35	1	1	1	100

Source: Office for National Statistics 2004a  
\* Respondents to this question were either married or living as married.

**TABLE 9: ECONOMIC ACTIVITY RATES IN THE UNITED KINGDOM, BY GENDER, 2000 TO 2003**

Gender	Economic activity rates (%) <sup>1</sup>			
	2000	2001	2002	2003
Men <sup>2</sup>	84.6	84.1	83.9	84.1
Women <sup>3</sup>	72.9	72.8	73.0	73.0
<b>All</b>	<b>79.0</b>	<b>78.6</b>	<b>78.6</b>	<b>78.8</b>

Source: Office for National Statistics 2004c

<sup>1</sup> Percentage of the population that is in the labour force at spring.

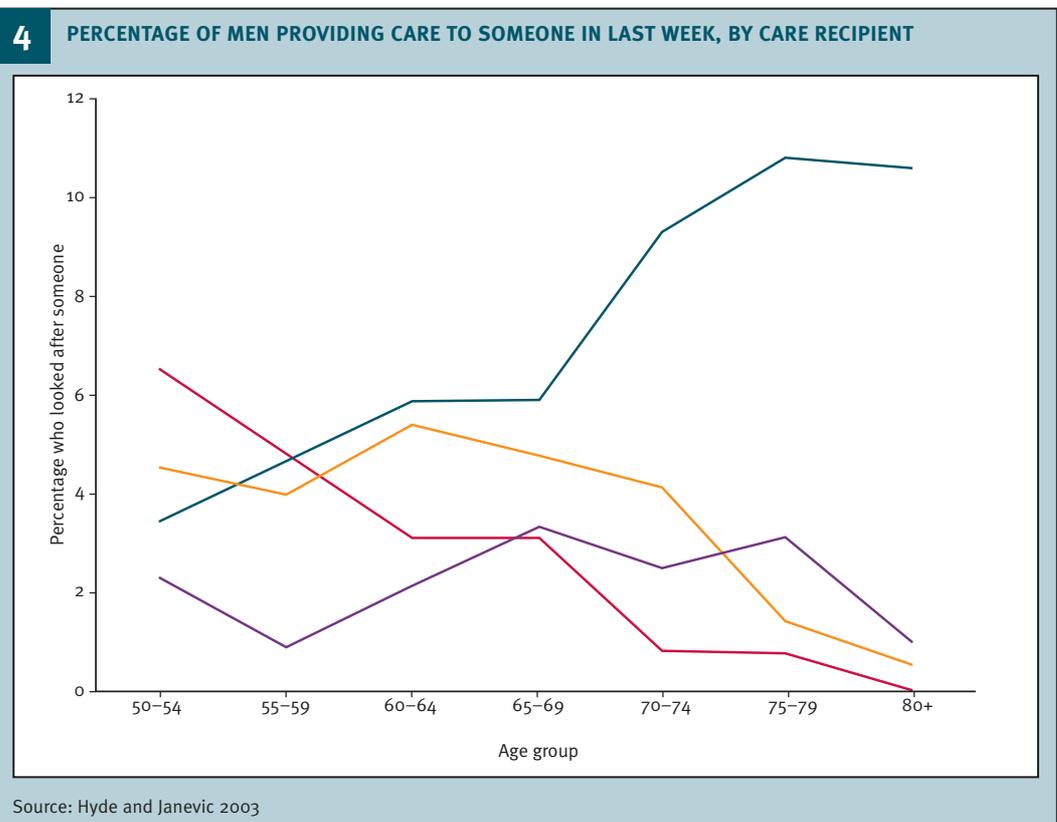
<sup>2</sup> Men aged 16–64.

<sup>3</sup> Women aged 16–59.

Note: Data is seasonally adjusted, and has been adjusted to take account of the Census 2001 results.

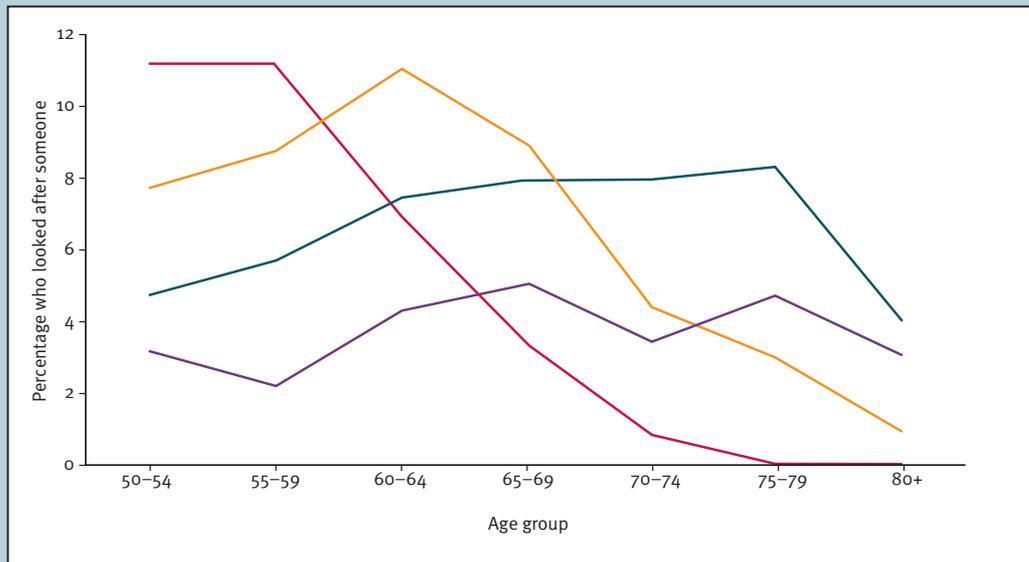
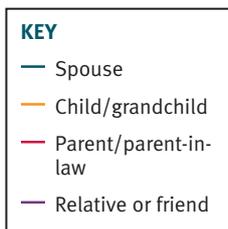
### Economic status/income

The evidence is inconclusive on whether the wealth and economic status of a person have an impact on the likelihood of providing informal care. Some argue that those from less advantaged backgrounds are more likely to provide intensive care, especially to a spouse/partner (Young *et al* 2005) (possible reasons for this include higher levels of poor health and disability in manual groups). Opposing this view, however, is the assertion that wealth is not a deciding factor in the provision of informal care; additional income does



## 5

## PERCENTAGE OF WOMEN PROVIDING CARE TO SOMEONE IN LAST WEEK, BY CARE RECIPIENT



Source: Hyde and Janevic 2003

not reduce the probability of individuals providing informal care, if other factors are constant (Leontaridi and Bell 2005).

The correlation between employment status and caring is more certain. Caring rates are higher (21 per cent) among the economically inactive (that is, not specifically seeking work because of retirement, long-term illness and so on) compared with full-time workers (13 per cent), part-time workers (17 per cent) and unemployed individuals (15 per cent) (Maher and Green 2002). As is the case with the relationship between gender and propensity to care, it is not clear whether caring responsibilities have an impact on economic activity or are the result of it. ONS data from the Labour Force Survey show that, of those who give 'looking after family or home' as a reason for economic inactivity, 23 per cent said that they did not want a job, in comparison to the 7 per cent who did want a job but had not sought one for the past four weeks (ONS 2005b). This suggests that, although the caring role may have some impact on workforce participation, it is not the only factor. This is discussed in greater detail below.

An additional consideration is the impact that caring responsibilities has on carers. Performing a caring role can have enduring negative financial consequences, including reduced income and pensions and likelihood of employment. This can have major implications for the economic status of carers, and is discussed further below.

### Education

Level of education has some impact on the propensity to care. Higher levels of education appear to reduce the probability of caring (for those living outside the household of the care recipient) (Machin and McShane 2001).

## Location

The provision of informal care across the United Kingdom varies considerably by region and local authority. There are some general trends that can be identified.

- Very rural areas in England and Wales generally have a higher proportion of adults providing care (ONS 2004d, 2004h).
- There is some degree of clustering of higher propensity to provide informal care in the heavily industrialised areas, such as the West Midlands, and the industrialised parts of northern England (see Figure 6, ONS 2004h). It has been suggested that there may be some correlation between levels of informal caring and levels of deprivation and poor health (Young *et al* 2005), although the evidence is not conclusive.
- There are generally lower levels of caring activity in the more affluent areas, such as London and the south-east and south-central England. For example, in 2001, the lowest proportions of adult carers were concentrated in London and the south-east, the 10 lowest all being inner London boroughs (ONS 2004d).

In addition to the location of the carer and care recipient, their proximity to each other can have an impact on the likelihood of caring. This is particularly the case where a child is the carer. Unsurprisingly, the further a child lives from the parent, the less likely it is that he or she is able to provide care on a regular basis. This correlation is not, however, as prevalent in situations where the 'care' from the child is in the form of funding for formal care interventions for the parent.

## Ethnicity

Research in England and Wales on the correlation between informal care and ethnicity has been limited. Findings from the small-scale studies that have been done suggest, however, that ethnicity does have an impact on propensity to care, with prevalence being highest among Bangladeshi, Pakistani and Indian groups (discussed in more detail in Young *et al* 2005). It is suggested that this difference can be explained through socioeconomic factors, such as intergenerational households, although cultural factors and differing levels of health and employment among different black and minority ethnic groups may also have an impact (see Young *et al* 2005).

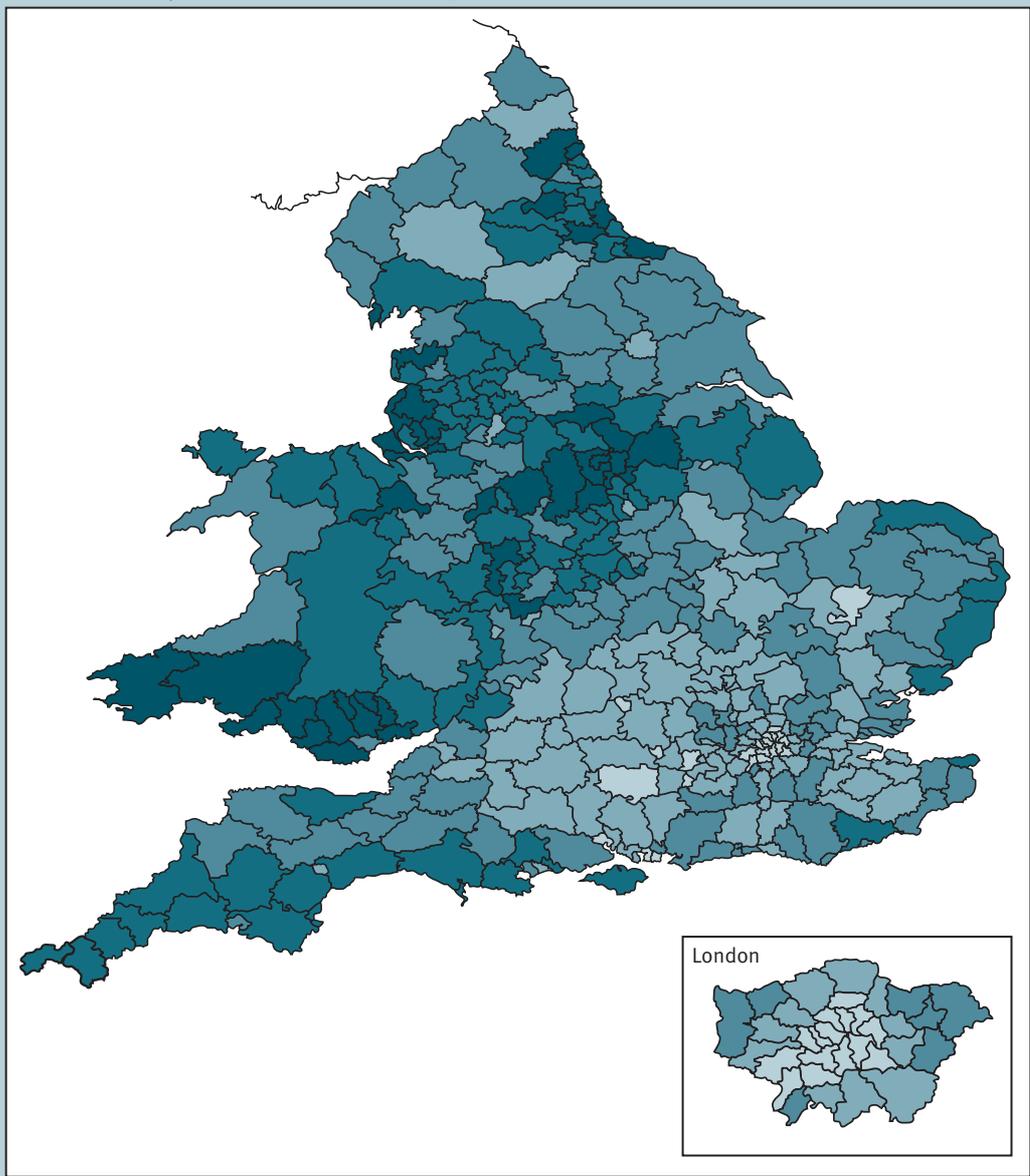
## Carer support services

There has been increasing recognition in recent years of the importance of providing support for carers both in their caring role and in their personal circumstances. This has been particularly evident, for example, in the National Strategy for Carers (Department of Health 1999), the 2006 health and social care White Paper (Department of Health 2006) and the inclusion of carers' support in social services' performance ratings (Commission for Social Care Inspection 2005). The rights of carers and the obligation of local councils in addressing these have also been addressed in legislation through the Carers Recognition and Services Act 1995, and further refined in subsequent Acts in 2000 and 2004 (Carers and Disabled Children Act 2000, Explanatory Notes to Carers (Equal Opportunities) Act 2004).

Despite these important legislative developments, there often appears to be a considerable discrepancy between what carers can 'reasonably expect' to happen and to receive, and their actual experience. Table 10 overleaf shows government information on

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PERCENTAGE OF PEOPLE IN HOUSEHOLDS, AGED 16+, PROVIDING UNPAID CARE BY UNITARY AUTHORITY/LOCAL AUTHORITY DISTRICT, APRIL 2001



**KEY**

7.82–10.44%
10.45–11.99%
12.00–13.08%
13.09–14.29%
14.30–17.33%

Source: Office for National Statistics 2004j  
 This table was prepared from the standard Census table SO25.  
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**TABLE 10: NUMBER OF CARERS RECEIVING CARER ASSESSMENTS AND SERVICES, 2004/5**

	Number of carers (thousands)
<b>Carer assessments</b>	
Carers assessed or reviewed separately	46
Carers assessed or reviewed jointly	148
Carers declining an assessment during the period	30
<b>Carer services</b>	
Carers receiving 'carer specific' services	65
Carers receiving information only	79

Source: Based on Department of Health Referrals, Assessments and Packages of Care Project data

the total numbers of carers receiving council assessments and services (NHS Health and Social Care Information Centre 2005). To put these numbers in context, the lowest estimate is that 3.4 million people are caring for older people (derived from the Census). If it is assumed that only those people providing at least 20 hours a week would benefit from carer support (not necessarily a valid assumption), then only about 20 per cent of 3.4 million might apply – that is, 680,000 carers. The figures in Table 10 suggest that around 10 per cent of the 680,000 actually receive support services. The apparently low level of provision of information is of particular concern.

Table 11 opposite develops this by providing details on the services that the Audit Commission (2004) argues a carer can 'reasonably expect' to receive. This shows that there are issues around carer services and support with regard to not only the numbers of carers who receive services and assessments, but also the consistency of coverage and monitoring.

In addition to the services identified in Table 11, a range of other services might also be targeted on carers. Provision varies according to the type of service, as does the effectiveness and cost-effectiveness of the method of support. Table 12 (see page 16) provides a summary of the key aspects with regard to each of main types of provision (using information from Pickard 2004 and the Audit Commission 2004). It is clear that variability of services is found across all forms of support to some degree.

**TABLE 11: COVERAGE AND GAPS IN THE SERVICES THE AUDIT COMMISSION STATES A CARER CAN 'REASONABLY EXPECT', 2004**

Action	Impact	Progress/coverage	Gaps/problems
Identification of need (by primary care staff and councils)	<ul style="list-style-type: none"> <li>Reduces carer breakdown</li> <li>Care recipient benefits from early identification and contact with services</li> </ul>	<ul style="list-style-type: none"> <li>Generally good</li> </ul>	<ul style="list-style-type: none"> <li>Fragmented</li> </ul>
Provision of information in the form of literature, websites, call centres, verbal advice and training (from both local and national sources)	<ul style="list-style-type: none"> <li>Very important in helping carer to fulfil caring role</li> </ul>	<ul style="list-style-type: none"> <li>Received by varying numbers of carers depending on the type of information and the method of dissemination</li> <li>Lots of activity but needs to be more systematic</li> </ul>	<ul style="list-style-type: none"> <li>Varied coverage regarding content and availability</li> <li>Poor involvement and monitoring</li> <li>Shortage of training</li> <li>Lack of clear contact points for carers and professionals</li> </ul>
Provision of support (including breaks from caring and help for those who are working or want to return to work)	<ul style="list-style-type: none"> <li>Helps prevent health problems resulting from caring</li> <li>Valued by carers</li> </ul>	<ul style="list-style-type: none"> <li>Increased support for carers as a result of the Carers Grant but still only 'modest' resources provided</li> <li>A minority of councils provide 'good' support</li> </ul>	<ul style="list-style-type: none"> <li>Gaps in provision of support at crucial times, such as weekends, nights and hospital discharge times</li> <li>Limited packages of care</li> </ul>
Assessments (of both the person cared for and the carer)	<ul style="list-style-type: none"> <li>Essential for appropriate carer support and getting maximum value for money with the available resources/minimal cost</li> </ul>	<ul style="list-style-type: none"> <li>The picture is confused</li> <li>It appears only half of carers are receiving assessments (however, carers are perhaps being included in assessments of care recipients)</li> <li>Quality of assessments is generally good when they are carried out</li> </ul>	<ul style="list-style-type: none"> <li>Poor recording of information and monitoring</li> <li>Not widely promoted to carers</li> <li>A minority of carers and care recipients receive care plans</li> <li>Seen as 'gatekeeping' services</li> <li>Few staff trained in conducting assessments</li> </ul>

Source: Based on information from the Audit Commission 2004

**TABLE 12: PROVISION, EFFECTIVENESS AND COST-EFFECTIVENESS OF CARER SUPPORT SERVICES**

Type of service	Current provision	Effectiveness	Cost-effectiveness
Respite care and short breaks from caring, including day-care services, in-home respite services, institutional/overnight respite services and mixed carer support	<ul style="list-style-type: none"> <li>• Service most widely used/ provided but still only a minority of councils providing good support</li> <li>• Wide variation in amount, source and type available</li> <li>• In 1995, 5% of older people received sitting services, 24% received day care and 18% received respite care<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Some evidence of positive impact on carers' stress levels and health, and can help to prevent health problems resulting from caring</li> <li>• Offers psychological comfort so enhances well-being of carers</li> <li>• Produces high levels of satisfaction</li> </ul>	<ul style="list-style-type: none"> <li>• Can reduce delays and readmissions at key times, such as discharge from hospital and in emergencies</li> <li>• Results depend on individual circumstances of carer and type of respite care in question</li> </ul>
Carer support groups	<ul style="list-style-type: none"> <li>• Varied providers and availability</li> </ul>	<ul style="list-style-type: none"> <li>• No conclusive evidence</li> </ul>	<ul style="list-style-type: none"> <li>• No research done</li> </ul>
Social work and counselling support	<ul style="list-style-type: none"> <li>• Received by a minority of carers – in 2000, 18% received therapeutic social work<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Reduces subjective carer burden</li> <li>• Relieves carer distress</li> <li>• Can reduce psychological problems in carers</li> </ul>	<ul style="list-style-type: none"> <li>• Reduces subjective carer burden very effectively</li> <li>• No evidence that this extends time spent by care recipient in the community</li> </ul>
Further formal care services to older people	<ul style="list-style-type: none"> <li>• Targeted at older people who live alone rather than with carers</li> <li>• Increasing focus on personal care</li> </ul>	<ul style="list-style-type: none"> <li>• Reduces carer stress (but perhaps less well than services above)</li> <li>• Can postpone or reduce rates of institutionalisation among care recipients</li> </ul>	<ul style="list-style-type: none"> <li>• Significant savings when compared to the more costly alternatives</li> <li>• No more cost-effective at reducing carer burden or stress</li> </ul>
Multidimensional approaches, including community care packages such as MADDE <sup>3</sup> and Care Management in the UK, with different services of potential benefit to carers	<ul style="list-style-type: none"> <li>• Depends on care managers – majority of carers in the United Kingdom do not have access to care management</li> </ul>	<ul style="list-style-type: none"> <li>• Results depend on what services are included</li> <li>• In some circumstances, can reduce carer burden and depression</li> <li>• Can increase carer stress</li> </ul>	<ul style="list-style-type: none"> <li>• Results depend on what services are included</li> <li>• Perception of cost-effectiveness depends on who the service aims to help as these approaches are not good for the carer</li> </ul>

Source: Based on information from Pickard 2004 and Audit Commission 2004

<sup>1</sup> Based on Bauld *et al* 2000

<sup>2</sup> Based on data from Pickard 2004

<sup>3</sup> Medicare Alzheimer Disease Demonstration and Evaluation

# The current cost of caring

The costs of caring are not simple to define or to calculate; this is certainly an area with considerable research and information needs. There are various problems associated with any financial assessment of the costs of caring. The evidence base is poorly developed and information that is available is of debatable accuracy and considerable variability. Cost estimates are sometimes produced in a very inexact way, for example through use of bands for estimated numbers of hours of caring, rather than exact figures. This can mask important factors and makes calculations somewhat arbitrary. In addition, the underlying assumptions are problematic, especially with regard to constraints on levels of substitution and appropriate 'exchange rates' of informal for formal care. As a result of these complications, attempts to produce complete, or even partial, calculations are sparse and necessarily contested. Below is a brief account of the main 'costs' (financial or otherwise) resulting from individuals undertaking informal care responsibilities, which can be divided into costs to the individual and costs to the economy.

## Individual costs

The reasons why people provide informal care are complex. That people are motivated to do so is self-evident from the large numbers of people who do devote their time and effort in this way (*see also* Evandrou and Glaser 2003; Young *et al* 2005). Whether because of some sense of commitment, duty or emotional attachment, people provide care despite the potentially significant costs, which are frequently overlooked. Certain groups tend to fare particularly badly, as a result of their stage in life, personal circumstances or the needs of the person for whom the carer provides care.

### *Loss of income*

Carers typically suffer a loss of income if they forego employment opportunities. In practice, although there are many who manage to combine work and a caring responsibility, this is often difficult to achieve. Problems with co-ordination of care and insufficient flexibility in employment frequently create a situation in which an individual feels forced into a position where he or she has to choose between employment and caring responsibilities (Machin and McShane 2001; Arksey *et al* 2005). In addition, many carers experience difficulty in returning to work and experience demotion or reduced income as a result of interrupted employment history (*see* Arksey *et al* 2005).

### *Detriment to pension*

Access to 'second-tier' pensions also suffers as a result of issues around credits and eligibility (Evandrou and Glaser 2003), leading to longer-term financial loss or pressure to make up the financial shortfall (Thomas Coram Research Unit 2002). Women in the

immediate pre-retirement years fare particularly badly, because this is the peak time both for demand for care and for consolidation of pensions (Hirst 2002). Problems are further compounded by the detrimental impact that caring has on planning for retirement (see Arksey *et al* 2005). The ongoing issues for those who have breaks in their pension contributions and limited pension provision have also been recently highlighted by the Turner Report on pensions (Pensions Commission 2005).

### **Benefit issues**

It has been argued by many that the regulations around receipt of carers' benefits are overly restrictive, creating a disincentive to work (Arksey *et al* 2005). For example, the earnings threshold is set at a low level and receipt of Carer's Allowance is possible only if the carer has no more than minimal earnings, cares for at least 35 hours per week and the care recipient receives Attendance Allowance (AA) or Disability Living Allowance (DLA) at the middle or highest rate for personal care. As discussed above, the vast majority (85 per cent of all carers looking after someone aged over 65) care for fewer than 35 hours per week. As also discussed above, the trend appears to be away from residing with the care recipient, and thus carers are increasingly likely to be directly involved in care-giving for shorter amounts of time. Under current regulations, a large, and increasing, number of carers do not qualify for receipt of any benefits, and thus have very little incentive to undertake any caring responsibility (apart from obligation or commitment to the care recipient), and receive no recognition of the care-giving that they undertake.

Those caring for older people are particularly badly affected, despite reforms such as removing the upper age limit for Carer's Allowance in 2002 (Evandrou and Glaser 2003; Department for Work and Pensions 2005). Research suggests that differential treatment between carers of children and carers of older people also extends beyond benefits into areas such as flexibility and application of policies by organisations (see Evandrou and Glaser 2003).

### **Additional expenditure**

Carers may, and frequently do, incur care-related costs that they would not otherwise have borne. These can include the following:

- costs incurred as a result of the caring role, such as travel
- additional household expenses or services, such as extra heating and food
- accommodation costs where move of residence has taken place; this could include both lost opportunity to earn market rent and costs of adaptations (Pickard 2004).

### **Disutility**

There are potentially considerable indirect or non-financial costs of caring – that is, negative effects experienced as a result of the caring role. These include costs such as social exclusion, erosion of personal relationships and adverse effects on health (the last of these is of particular significance and is discussed further in the Annex, pp 36–8). Some attempts have been made to quantify the cost of disutility (see, for example, Brouwe *et al* 1999), but the result is necessarily arbitrary and reliant on very subjective factors such as how much someone dislikes carrying out a task.

## Economy-wide costs

The costs to the economy of informal caring are twofold: the direct cost of the services provided to carers, and the cost to the economy of the carers not being engaged elsewhere and thus not able to make an alternative contribution to the economy. At present there is little information on either. In Chapter 10 of the main report, carer support services, as they might be deployed in the future and their possible costs, are specified. The modelling work by Personal Social Services Research Unit (PSSRU) on current service patterns, detailed in the accompanying paper by Malley and colleagues (Research Paper 1 ‘Expenditure on Social Care for Older People to 2026’ in appendices) identifies costs of respite care services. These are estimated at around £200 million in 2007.

### *Indirect costs*

Costs at an individual level are clearly felt (as described above). Determining the cost of informal care to the economy, however, presents considerable methodological challenges. The initial reaction to the National Institute for Health and Clinical Excellence (NICE) for excluding these costs in its appraisal of new drugs for treatment of Alzheimer’s disease testifies to the strength of concern in this regard (see Box 1 and Chapter 9 in Wanless 2006).

#### **BOX 1 ALZHEIMER’S DISEASE DRUGS – NATIONAL INSTITUTE OF HEALTH AND CLINICAL EFFECTIVENESS (NICE) APPRAISAL**

The high level and cost of informal care for people with dementia have been debated following NICE’s appraisal of various Alzheimer’s disease drugs. People with dementia and their families argue that assessment of the cost-effectiveness of dementia care should include the hidden costs of informal care.

In its preliminary 2005 recommendation, NICE concluded that the drugs in question should not be used in the NHS (except meantime as part of certain ongoing clinical studies). It judged that the drugs lay outside the range of cost-effectiveness considered appropriate for the NHS.

The NICE evaluation found that the literature was sparse on the costs associated with Alzheimer’s disease, but that a significant proportion of these costs fell on patients and care-givers. A review of nine studies on costs for community-based people with Alzheimer’s disease estimated that the proportion of total costs represented by informal care ranged between 36 and 85 per cent (McDaid 2001). The wide range resulted partly from differences in the type of costs included and the methods used to quantify and value care-giver time. A cost study in Ireland found that family care accounted for almost 50 per cent of the overall resource burden for Alzheimer’s disease (based on an opportunity cost valuation of carer time) (O’Shea and O’Reilly 2000).

There was a fierce reaction to the NICE preliminary recommendations, with families and pressure groups strongly opposed to the suggestion that drugs should not be prescribed by the NHS. The then Health Secretary indicated that he had brought a number of questions to NICE’s attention:

- Had NICE carried out a cost-effectiveness analysis of this medication compared with non-drug interventions for cognition, behaviour, activity of daily living and carer burden?
- Would NICE consider including carer time when reassessing cost-effectiveness? In its response to NICE, the Department of Health asked: 'Has NICE considered whether there would be a different answer if the costs of carers as opposed to the benefits were included? Would this make a difference? It is our understanding that NICE generally only considers NHS costs. Is it satisfied that this is sufficiently wide-ranging to cover adequately all the potential benefits of the drugs involved? The care of people with dementia relies heavily on family caregivers. As there is data from randomised controlled trials on reduction in caregiver time as a benefit from these medications, would NICE reconsider re-assessing cost-effectiveness including a factor for carer time in the outcome?' (Department of Health 2005b).

In January 2006, NICE issued a revised appraisal saying that certain drugs should be available on the NHS but only to those with moderate Alzheimer's disease. In the economic modelling, an adjustment was made to cover the quality of life (utility) gains of carers that arose when an Alzheimer's disease patient in receipt of one of the drugs did not progress to later and more difficult stages of the disease within 5 years or because of death. However, it was decided that it was not appropriate for carer costs to be included in the economic model. It cited the potential for double counting if the effect on carers was incorporated as both improvements in utilities and some monetary value of the opportunity costs. In addition, current NICE guidance calls for the use of only NHS and PSS (personal social services) resources to be included. So, the hopes of users' groups were dashed that NICE's Alzheimer disease drug report might set a precedent for the opportunity costs of carers to be taken into account when assessing the cost-benefits of social care models.

### **State benefits**

In acknowledgement of their financial position and of the important contribution that they make, some carers are eligible to claim Carer's Allowance. This benefit is estimated to cost at least £19.7 million per week. As of August 2005 there were 441,000 claimants in Britain (Department for Work and Pensions 2006) and the basic benefit rate was £44.35 per week.<sup>4</sup> Carers can also be eligible for income-related benefits and premiums or in-work financial benefits depending on their situation (Arksey *et al* 2005). Given the complexity and repeated testing for entitlement, take-up can be low. It is believed that the introduction of 'individual budgets' (IBs) will help to streamline the process for claimants.

### **Lost contributions**

The level of contribution that individuals would be making to the economy if they did not have caring responsibilities depends on whether they would be working (more or at all) were they not in a caring role. As noted above, having caring responsibilities does not automatically result in withdrawal from the labour market, with even those who provide care for longer hours showing a relatively high participation rate. To illustrate, in 2000, just under half of all those caring for 20 hours or more a week were also in paid employment (Maher and Green 2002). Table 13 opposite gives details of workforce participation rates for carers in the United Kingdom (excluding Scotland).

**TABLE 13: DISTRIBUTION OF CARERS BY EMPLOYMENT STATUS, UNITED KINGDOM EXCLUDING SCOTLAND**

Employment status	Carers outside home (%)	Carers inside home (%)
Full-time employee	47.1	11.8
Part-time employee	17.7	3.1
Full-time self-employed	7.6	2.4
Part-time self-employed	2.3	1.2
ILO* unemployed	4.5	2.6
Retired	7.5	63.5
Student	0.5	0.2
Looking after family/home	4.0	2.8
Permanently sick/disabled	4.3	3.5
Temporarily sick/disabled	0.6	0.5
Other inactive	4.1	8.5
	<b>100.0</b>	<b>100.0</b>

Source: Family Resources Survey, cited in Machin and McShane 2001  
 \* International Labour Organisation definition.

There does, however, appear to be some impact on the decisions and behaviour of carers with regard to involvement in the labour market, with correlations existing between both length of time spent caring and the propensity to work, and the level of caring responsibility with the number of hours worked (both inversely proportionate). This seems be especially significant for women. For example, women providing more hours of care are more likely to be working part time (26 per cent) or not at all (58 per cent), whereas, for men, 47 per cent or those caring for 20 hours or more also work full time, although 46 per cent of men caring for 20 hours or more do not work. In addition, employed carers of both sexes under the age of 75 are less likely to provide round-the-clock care and more likely to provide light care (less than 20 hours of care per week) than their economically inactive counterparts (Bass and Caro 2001).

Furthermore, the likelihood of a person returning to work is affected, as are the wages and position of the employee compared with those before the caring break. For those who participate in the workforce throughout caring episodes, employment is frequently compromised by factors such as the need for flexibility, restrictions imposed for benefits and other responsibilities. Research has found that there are various problems encountered by carers returning to work, whereas the effectiveness and suitability of the support received by carers (for both working carers and those who wished to return to work) are less than ideal (see Arksey *et al* 2005).

It is noteworthy that the perceived impact of the caring role on workforce participation is significantly higher than the figures suggest is the case (Machin and McShane 2001). For example, Family Resources Survey data show 36.4 per cent of carers (in the United Kingdom, excluding Scotland) claim caring affects their labour participation (Machin and McShane 2001). This perception of interference is far higher among those who live with the care recipient than for those living in another household (83.8 per cent versus 27.5 per cent). As illustrated above, however, the employment figures show that around 75 per cent of all carers are in some form of paid employment. This gives some indication that the

caring role may have some impact on optimal employment as well as actual employment rates. This is consistent with work by the Care Development Group suggesting that, although the support and incentives offered have an impact on the decisions made and the outcome with regard to labour participation, it is unlikely that people chose directly between care and the labour market.

Measuring the economy-wide costs of caring is problematic. There are two broad approaches. Costs can be measured either in terms of what it would cost to replace informal care inputs with formal care (market replacement cost) or as the income/working and leisure foregone as a result of time being devoted to caring. The former is likely to under-estimate the full economic cost, but the latter is demanding to calculate and involves assumptions about the value of work and leisure for people. Nevertheless, there have been attempts to estimate these costs. Examples cited by Pickard (2004) include consideration of aspects relating to both the individual and the economy, such as direct expenditure, foregone waged and non-waged time, and foregone career prospects and accommodation income. Estimates by Netten *et al* (cited in Pickard 2004) were of a cost to the carer of £31.42 per week and to society of £29.98 overall in 1990. After uprating by inflation (using a gross domestic product [GDP] deflator), this is equivalent to costs per carer in 2006 of £47.13 and £44.97 per week, respectively. If this were to be applied to all those currently caring for people aged over 65, it would suggest a cost figure of £9.4 billion to 'society' overall. In addition, Chapter 10 of the Wanless report (Wanless 2006) estimates replacement costs of £3.5 billion using the projection model. This difference in figures is consistent with the expectation that full economic costs will exceed replacement costs.

## Future position

There are two ways in which rates of informal care can be expected to change in the future. First, if patterns of informal care remain constant with respect to personal characteristics, then the changing circumstances of older care recipients will affect the likelihood that informal care will be available. If, for example, there are more older people living alone, the overall rate of informal care will be lower (because people living alone receive less informal care than those sharing a household). Second, patterns of informal care may *not* stay constant. For example, people who might currently be prepared to care for those in need in certain circumstances may not be so willing in the future.

The general conclusion on the basis of the evidence available is that it is unlikely that rates of informal care will keep pace with increases in care needs in the future. There are several trends that lead to this assertion, in particular:

- the number of people requiring informal care will rise at a faster rate than the supply of informal care
- the nature of care is changing. Most important is the increase in care provided from outside the household, which is for fewer hours per carer than if it was provided by a co-resident carer, and providing less of the more intimate forms of care, such as personal care.
- care recipients will arguably expect increasing levels of independence (requiring greater input), whereas carers also have higher expectations with regard to their own freedom.

This combination of factors has the potential to create a gap between the available supply of informal care and the demand, both quantitatively and qualitatively.

In Chapter 10 of the main report (Wanless 2006), numbers of older people who will be supported by informal care in the future are estimated. Assuming that current rates of care hold in the future, the central projection of this model would require an increase of informal care input of just over 50 per cent between 2002 and 2026 – details of these assumptions are given in Research Paper 1 ‘Expenditure on Social Care for Older People to 2026’ of the appendices.

There are several factors influencing the future availability of informal care that are worthy of note. These are discussed briefly below.

### ***Increasing age of carers***

Whether spousal/partner care will keep pace with the projected increase in demand for care will depend, not least, on the health status of those spouse/partner carers themselves. The age of the caring population as a whole will increase. Research suggests that the relative age of spouse/partner carers in particular is increasing relative to other forms of informal care supply. This is a trend that is set to continue, and will result in an increased age of the carer population as a whole. It is projected that the number of elderly carers will be greater, particularly when those born in the post-World War II baby boom reach their 70s and beyond (Hirst 2001). This has possible implications for the care provided, in terms not only of tasks and hours of care, but also of the nature of the support required for the carers themselves.

### ***Decline in filial co-residence***

As we have noted throughout, the volume of hours spent caring is much higher among those who co-reside with the care recipient. Most of those caring for people living in another household care for fewer than 20 hours per week (89 per cent) and there has been a significant decline in co-residence between adults and elderly parents (Grundy 1999). The implication of a trend towards care being provided by carers living in a different household is that the number of hours spent caring will decrease, specifically for the tasks that are largely currently undertaken by those who live within the household, such as personal care. Furthermore, there is a decline in more intensive and demanding care where the carer lives apart from the care recipient, and increases in the intensity of care within households, particularly for elderly spouses/partners (Hirst 2001).

### ***Changes in living arrangements***

There are several changes evident in the patterns of living arrangements of older people and the population as a whole that have the potential to impact considerably on the availability of care. As highlighted above, there has been a notable increase in the number of one-person households (ONS 2005a). One reason for this has been the decline in filial co-residence (see above). In addition to this, however, is a general trend towards higher levels of divorce and lower levels of marriage (ONS 2004f). Although this is partially offset by increases in co-habitation outside marriage (ONS 2004g), there is inevitably an implication for the future circumstances of older people and the amount of care that will be provided on an ‘informal’ basis. As the care provided by children declines, decreases in the level of spousal support will also have direct implications for the formal care required.

## ***Expectations and attitudes***

Expectations about quality of life and levels of independence have risen, and will continue to rise, among recipients and carers. Care recipients have growing expectations of support that will enable them to have increased freedom and independence. Carers' expectations might also be argued to reflect the increasingly atomistic perspective of society, where the principles of choice, rights and autonomy are valued above those of community and responsibility. This is in line with a school of thought that suggests that the filial responsibility previously visible is eroding, and that 'fixed obligations' no longer compel to the extent seen previously (Finch 1995). Although there are many who disagree that this change in mindset is taking place and point to the continuing high levels of support that carers provide, it is clear that the automatic obligation for kith and kin seen in previous generations can no longer be assumed to be the case.

Reconciling such conflicting views might require increasing clarity on the role of formal care and the rights that it should support for the individual, including, for example, the right to personal independence. With regard to caring there seems to have been a move towards the assumption that, when a person foregoes his or her individual rights, such as sacrificing his or her time by caring for someone else, he or she should be compensated to a degree by the rest of society, that is by the public purse. This is illustrated in the case of *Stephenson vs Stockton on Tees Borough Council* 2005. In this instance, a claim was made for reimbursement of payment made to the daughter (the carer) for care provided. This was lost on the basis that it was considered reasonable to expect family members to look after elderly relatives out of their own finances.<sup>5</sup> It appears that the current legal perspective supports the idea that family members should be expected to provide care through love and obligation, and should not be compensated for this time unless extraordinary circumstances dictate otherwise. This is a view that is being increasingly challenged.

In addition to the numbers of people requiring care rising at a faster rate than the supply of informal care, the nature of the care provided will change, for example with an increase in care provided from outside the household. This shift would mean fewer hours per carer and less provision of the more intimate forms of care, such as personal care. Meanwhile, care recipients will arguably expect increasing levels of independence, thus possibly requiring greater formal care input. This combination of developments seems likely to create a widening gap between the available supply and the required care inputs; projections of the extent of this are developed in Chapter 10 onwards of the main report (Wanless 2006).

It has been argued that there is a general willingness among large sections of society to continue caring in the community, as long as the characteristics of the carer, the care recipient and the care-giving environment are conducive to this. Ensuring that this disposition actually translates into care will, however, need provision of sufficient support of an appropriate nature. Major questions exist about what form this support should take. It is this issue that is now addressed.

# New strategies on informal care

## **Supporting carers**

There are broadly two schools of thought on the best way to support the four million carers who play such an integral role in the support and care of older people in England. On the one hand, there is the argument of those such as the Royal Commission on Long Term Care (1999, Pickard 2004), which suggests that the best way to support informal carers is to improve the services offered to those who are currently recipients of informal care. The Royal Commission proposed moving towards a ‘carer-blind’ situation, where the existence of a carer does not impact on the likelihood of services being offered to the individual by the state (discussed in Pickard 2004). This would include approaches such as the substitution of current informal provision by formal care (discussed below). The alternative approach is to provide services to the carers themselves, in order to support them in caring for the individual whom they are looking after.

## **Support services**

The current provision of services to support carers in their role varies significantly with location and personal circumstances (such as residential status). This is discussed above (see pp 12–15).

As discussed above (and in the Annex, pp 36–8), the evidence for the cost-effectiveness and effectiveness of carer support services is varied. The impact of services on carer outcomes can be judged in (at least) two ways: first, in the way that services delay the need for people to enter permanent residential care (because it delays a breakdown of the caring situation at home); second, in the way that services directly impact on measures of carer stress. On this basis, there is evidence that some types of support for carers can be effective (Pickard 2004). Davies and Fernández (2000, in Pickard 2004), for example, find that social care services, and especially day care and respite care, are effective in both ways. Social work can also be highly effective in tackling carer stress.

Improving the situation of carers also has consequences for their employment opportunities (and so broader economic performance considerations). In principle, reductions in carer stress ought to go hand in hand with improvements in the working situation of carers (even where work cannot be continued, opportunities to develop human capital during a caring episode would help maintain employability and keep skill levels at a preferred level). Similarly, reductions in these ‘costs’ of informal care to potential carers are likely to improve the supply of informal care. It might also be an effective strategy to cover some of the financial costs of caring, as discussed above. However, there is no direct evidence to confirm such speculation.

Improvements and increases in carer support should also directly impact on the quality of care provided. A less stressed, overworked, unhealthy or tired carer should have an increased capacity to care, and there is likely to be a generally improved atmosphere in the caring situation. In addition, training support should mean care of a higher quality.

The Wanless Review recommends that evidence on the cost-effectiveness of services with regard to delays in institutionalisation and carer outcomes is developed, and used, together with that which is currently available, to justify further investment in carer services.

## ***Incentives***

Many other countries have similar benefits for carers or allow direct payment or care budget equivalents to compensate informal carers. Looking at the example of other Organisation for Economic Co-operation and Development (OECD) countries (using the example of Lundsgaard 2005), there are three main ways in which payment is provided for informal care:<sup>6</sup>

- personal budgets and consumer-directed employment of care assistants
- payments to the person needing care who can spend it as she or he likes but must acquire sufficient care
- income support payments to the informal care giver.

All of these methods have advantages and disadvantages. It is not possible to discuss these in depth here (although Box 2 oopposite looks at the situation in Germany). Drawing on the evidence from abroad, however, it appears that paying carers has a range of possible consequences.

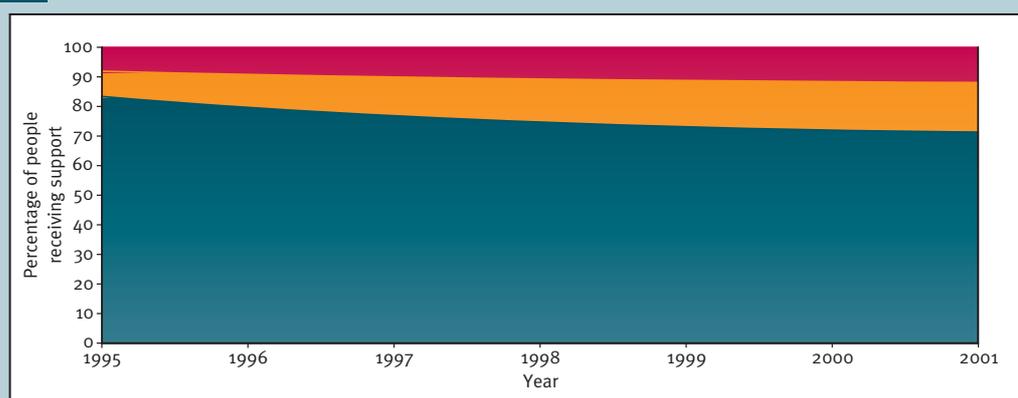
- There are potentially ‘deadweight’ costs in reimbursing carers who would, without payment, maintain their levels of caring in any event.
- Some claim that carer payments creates ‘incentive traps’ that attract carers away from the labour market. This could be argued to be the case in Luxembourg, where the age group most susceptible to adverse incentives, that is 50- to 59-year-old women, show lower economic participation rates (Lundsgaard 2005).<sup>7</sup>
- Carer payments help people who choose to care for loved ones even though they bear significant adverse financial and other consequences.
- Even a relatively small payment can induce a significant supply of care as the experience in Germany – where an older person’s cash payment for care can be used to pay carers – testifies.

Payment for informal caring potentially improves carer supply as well as providing compensation to carers for some of the costs of caring. If people want to provide care despite the opportunity costs that they face, paying them will improve the outcomes for those carers, but may not induce more people to care than would otherwise have done so in any case. Alternatively, if payment sufficiently offsets the opportunity costs of those who otherwise would not care, overall carer supply will increase, but the net effect on the economy is likely to be negative. However, if the opportunity cost is not much greater than the replacement cost of care, and both the carer’s and the care recipient’s outcomes are better with informal rather than formal care, a case would exist for carer payments. Furthermore, there are strong fairness and moral arguments that, where people provide care and their financial and other circumstances are reduced as a result, help should be provided.

## BOX 2 PAYING FOR INFORMAL CARE: THE EXAMPLE OF GERMANY

In Germany payments have been used for informal care in a way that is similar to the initiative seen in this country of direct payments. Under the German system, the care recipient can opt to receive a cash allowance to cover informal care, in particular by a relative. A majority of beneficiaries have chosen this option even though the amount of cash is markedly less than the equivalent in formal services. As a result, the programme has actually run at a surplus, allowing the government some flexibility over establishing new service-providing organisations (Creighton Campbell 2002). When given the option of receiving a greater amount of service provided formally, or less under the direction of the individual, it is perhaps surprising that there has been such a huge move towards taking the less financially valuable cash option – although there has been a decrease in choice of the cash-only option over time, it is still the option taken by a huge majority of care recipients. Notably, this is not only for those in need of more intense care but a trend that is visible throughout the system. This is illustrated in Figure 7 and Table 14.

## 7 CHANGING COMPOSITION OF CHOICES OVER TIME IN GERMANY, 1995 TO 2001



Source: Federal Statistics Office Germany, cited in Lundsgaard 2005

KEY	
■	Services only
■	Combination of cash and services
■	Cash only

**TABLE 14: CHOICES MADE BY GERMANS SUPPORTED BY LONG-TERM CARE INSURANCE, 1998**

Level of care need	Choices of people receiving support			Average share of cash for persons choosing a combination of cash and services (%)
	Cash only (%)	Combination of cash and services (%)	Services only (%)	
1 – lowest	82	8	10	42
2 – middle	77	13	9	35
3 – highest	64	25	9	39

Source: Lundsgaard 2005

Any conclusions to be drawn also depend on the supply of formal services, an issue explored in Chapter 7 of the main report (Wanless 2006) and background paper 5 of the appendices ('The Social Care Workforce in England'). If formal care supply is limited, then inducing more informal care would imply a significant improvement in care recipients' overall outcomes, especially where needs would otherwise remain unmet. It is not clear that the supply of informal care will meet projected demand for care in future years (Pickard *et al* in press). Without some introduction of incentives or support for people, it is difficult to see how the gap could be closed from the informal care side.

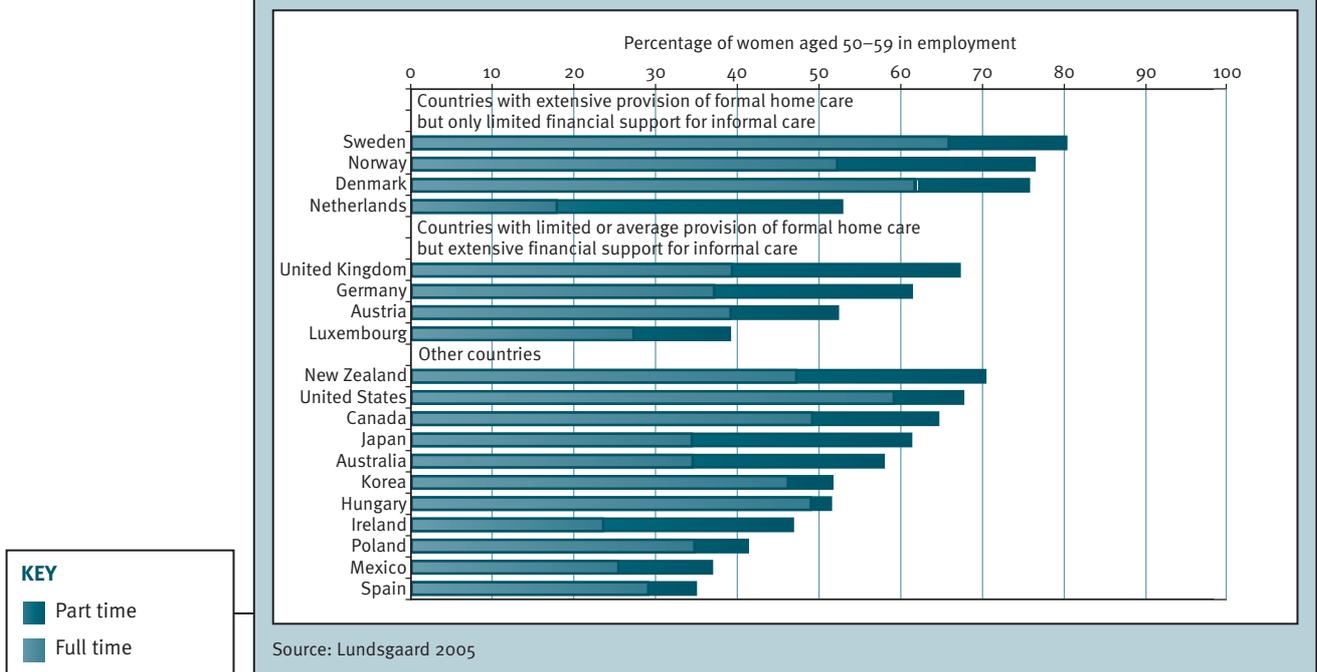
Where payments are forthcoming, the situation of carers will be improved. This could be achieved by either reimbursing carers directly (for example through benefits) or allowing them to be paid from a care recipients' cash payment for care.

The care recipient would benefit from these incentives to carers if the formal care remained unchanged. The potential problem, however, is that formal care might be reduced. Paying carers from a fixed overall budget clearly diverts resources. This problem will be compounded if wider economic performance is also affected by the withdrawal of carers from the workforce. Ideally, the care recipient and the carer would be jointly assessed and services deployed, as needed, to address outcomes for them both. The Older People's Utility Scale (OPUS) could be used to develop tools to measure the impact of services on care user outcomes (see Chapter 5 of the main report). It is recommended by the Wanless Review that further work is undertaken to extend this scale to account for carers' outcomes.

## Increased formal care to older people

Increases in mainstream formal services to older people appear to have little impact on how much informal care is provided. Work done by the Care Development Group for the Scottish Executive (Leontaridi and Bell 2005) suggested that evidence for substantial substitution away from informal care, as a result of the extension of formal provision of care services, is weak. More recently, following increased formal provision under Free Personal Care in Scotland, little evidence could be found of a reduction in informal care (Bell and Bowes 2006). This is consistent with evidence from controlled experiments on substitution between formal and informal caring in the USA, in an environment where informal care was already being provided; research showed that, after 6 months, the amount of personal care provided formally had increased by 25 per cent whereas the amount provided informally had declined by only 3 per cent. This indicates that, even when formal care provision is offered, individuals providing care do not easily 'opt into' work in the labour market (Leontaridi and Bell 2001; Machin and McShane 2001).

There is some apparently contradictory evidence, however. In Denmark a positive correlation between greater emphasis on formal provision of care and greater workforce participation – particularly for women aged between 50 and 59 years – has been identified (Lundsgaard 2005). However, research suggests that that this change of emphasis needs to be combined with other factors to ensure that the net result is increased labour force participation rather than the opposite. In Denmark, for example, the policy of reducing dependence on informal care was undertaken together with other welfare policies and the extent to which the strategy on formal care has been directly responsible for the changes seen has been very difficult to identify. The Netherlands provides another example where



lower levels of workforce participation have been apparent, despite an emphasis on formal care. Figure 8 above illustrates the relationship between approaches to informal care and the participation rate for women of selected ages. Although it is not possible to draw conclusions from this information alone, it is possible to conclude that no single approach appears to hold a key to facilitating higher female workforce participation rates.

This would support the findings of research done for the Department for Work and Pensions (Arksey *et al* 2005), which found that decisions about caring and employment status are influenced not only by finances, but also by a range of factors, with no single factor dominating the final decision. The possibility of earning more through employment is not necessarily sufficient in itself to entice people to cease or reduce their caring responsibilities.

A greater availability of care services for the older person would improve carers' outcomes but arguably not as effectively as formal services tailored to supporting carers. This is particularly the case with spousal/partner carers, who are overall less likely to reduce their input than filial carers. With regard to filial carers the situation is less clear cut, with the level of informal care provided and the likelihood of returning to the labour market being influenced to a greater degree by the support that is received. Where the care recipient's children are the primary care givers, the case for care services as well as carer support services is strengthened as part of a strategy to improve carers' outcomes. Effective support for filial carers could then be provided through a range of options.

Although practical support is essential, it is not the only aspect that needs to be addressed. Increases in formal care provision alone will not ease the financial burden on those who do care. Moreover, if formal services do not induce carers to reduce their own inputs much, then the opportunity to earn is not increased to any significant degree.

## Alternative and development options

In addition to the approaches discussed above, there is also a range of other, potentially more wide-ranging options for informal care in England. These options could include the following.

- **Further engagement and support of local community and voluntary networks:** the use of *Time Banks*, for example, is embryonic in this country, but experience from the USA, in particular, is promising.
- **Further development support services:** this could include both new types of services, such as home sharing, and existing services such as adult day care.
- **Promoting greater support for carers from employers:** examples of good practice do exist in some organisations, but the onus is currently on employers. This needs to be developed, particularly with regard to both working practices for working carers and support for retired employee carers.

# Other issues to consider

Specific policy on carers now and in the future is also affected by other considerations.

## **Perceptions, responsibility and expectations**

As discussed above, there are increasing expectations about personal independence among both care recipient and carer alike, which may lead to a widening gap between the available supply and the required care inputs, with obvious implications for provision of care.

This is compounded by the absence in the UK of clarity on the respective responsibilities of the state, family and individuals with regard to aspects such as care. Countries such as Spain and Korea have a more explicit understanding that the responsibility lies with the family, leading to the expectation that care will be provided on an informal basis with no financial reimbursement from the state. The USA meanwhile is also clear that US state intervention is considered only as the avenue of last resort. In the UK, however, there is no defined approach towards care of elderly people, for example, with the system relying entirely on assumptions and implicit expectations rather than clear direction.

The very existence of a welfare state, and the explicit guarantees with regard to free health care for all, suggest that the state accepts responsibility for people who are weak, vulnerable and in need. However, there seems to remain an implicit expectation that the family retains the ultimate obligation for supporting and looking after their relations, especially with regard to ongoing social care. Before any decisions are made on the direction of informal care, it is necessary to have an open and public debate on the question of family obligations and the role of the state. Policy can then be formulated on a more transparent basis, with a clear rationale for direction, and the responsibilities of each party made explicit

## **Regulation and quality**

In an unknown number of cases informal caring brings with it risks of abuse, neglect and poor care. There is, for example, a perceived lack of monitoring of the informal caring situation, and there are consequent problems in detecting and preventing abuse. The fact that informal carers are not included in the Protection of Vulnerable Adults scheme, and currently do not have to undergo any checks or assessments (such as Criminal Records Bureau (CRB) checks) to provide care to potentially vulnerable adults, is indeed of possible concern. Evidence from abroad suggests, however, that selection and management of care by the user do not necessarily lead to problems of neglect or poor hygiene, apparently as a result of the actual oversight of the vulnerable people by other members of the community (Lundsgaard 2005). More work is required to weigh the

benefits, in terms of better quality and safety, against the costs, and the conclusions need to be acted on in future policy.

There are legitimate questions to ask about the potential for risk and abuse, especially given the possible expansion of direct payments (DPs) and individual budgets (IBs), and the increased reliance on judgements and choices of the care provider by the care recipient that this entails. These would include:

- how do we ensure that there is no pressure on the individual from the family member (for example) to employ them?
- how do we ensure that a care recipient is receiving care from the person paid to provide it?
- how does vulnerable adult protection work in this scenario? Should it be applied?

Inextricably linked to the question of regulation is that of quality. As discussed in background paper 5 of the appendices ('The Social Care Workforce in England'), there are significant challenges in defining quality in formal care. This issue is made more complicated in informal care by the fact that carers are not regulated or assessed. It is unlikely then that any regulation could take place, bar the introduction of compulsory assessments or appraisal-style interviews. It is not possible to say, however, how viable or cost-effective monitoring and assessment of the quality of care provided would be without proper examination. It is likely that the cost would be significant. There are initiatives that could possibly contribute to an increase in quality, such as training of informal carers, but it is unclear to what extent this would improve the quality of care received or the situation of the carers, although it is likely that help with specific aspects, such as lifting and handling, would be beneficial to both the carer and the care recipient.

As discussed in background paper 5, the cost of training varies considerably depending on the circumstances of the individual in question, and the evidence for the effectiveness of various different types of training available is inconclusive. There are also issues around the capacity for training and the availability of appropriate trainers. It is not possible to recommend a course of action on the basis of the information currently available. It has been recommended in the main Wanless report (Wanless 2006) that additional research is needed before any decisions are made on changes in the training provided, and additional information should be obtained on the existing capacity and scope for expansion. This would also apply in the case of informal carers.

## Choice

The choice agenda is one that has been conspicuously prominent in recent health care and social care policy. Although some initiatives have extended this choice emphasis to carers and care recipients, this has been limited and is not all inclusive. As mentioned above, the use of DPs and IBs, for example, has been extended by the 2006 White Paper (Department of Health 2006) – a development that seems to have been generally well received. Despite the assertion that DPs are already available to carers, this does not include co-habiting relatives except under exceptional circumstances (see Sections 9 and 15 of background paper 3 in the appendices 'Direct Payments and Older People'). It is currently not clear whether this proposed extension includes this group, and what the practical implications will be, that is whether councils with social services responsibilities (CSSRs) will continue the actual policy of excluding these groups from the DP remit.

The payment of informal carers is certainly linked to the choice agenda, with the option to have a relative or friend as carer (and vice versa to provide care for a relative or friend) being seen as a central element of choice in a very direct sense (Lundsgaard 2005). As noted above, there are a range of pros and cons on both sides of the debate (especially concerning close relatives). This will need to be resolved. There is not yet sufficient evidence to form a view on which direction should be followed. It is recommended that additional research be done on this question, and the results used to inform future policy.

# Conclusion

Informal (and unpaid) care plays a vital role in the support of older people. Very large numbers of people provide at least some level of care, with some providing a very substantial input. Key questions are:

- should we continue to rely on informal care?
- if yes, what are the consequences?
- are the resultant situation and outcomes for carers reasonable?
- is the supply of informal care going to keep pace with the probable increased demand for care?

Given continuing demand and also the willingness of many to care for others, it is inevitable that informal care will continue to provide a significant input. Many people take on caring responsibilities with little regard for ‘substitution potential’ of formal care and are motivated by many factors other than the provision of formal care or lack of it. Moreover, as detailed in Chapter 10 of the Wanless report (Wanless 2006), the costs of increasing formal care to address unmet need arising from a reduction of informal care would be prohibitively high, even if the trained workforce could be created in sufficient numbers (see Chapter 7 of the Wanless report).

Based on current patterns, it is expected that informal care rates will fall short of increases in levels of demand for care. Furthermore, at present, outcomes for some carers deteriorate to unacceptable levels. This can be expected to continue into the future if current arrangements persist. There are solutions ranging from improving support services to carers and payments for carers, through to broader attempts to foster better societal attitudes to caring.

The evidence base is not as developed as it might be, but the case for further carer support services looks strong. The cost and outcomes implications of this are modelled in ‘The current cost of caring’ (pp 14–23). For spousal/partner carers, the best form of support seems to be services that address carers’ outcomes directly, relieving some of the pressures of care. For filial carers, this argument also holds, but the case for possible substitution of informal care by formal services for the care recipient is stronger. The implications of a ‘children carer-blind scenario’ are examined in Chapter 10 of the Wanless report (Wanless 2006).

There are also strong fairness arguments, particularly around supporting those people committed to caring whose financial and other circumstances are consequently reduced to low levels. This argument can support a case for extending financial support for all carers. It is reasonable to expect that those individuals fulfilling the perceived obligation of caring for the vulnerable should not be actively disadvantaged, either financially or personally, and are not driven to poor health through excessive demands.

These arguments concern not only the implications for the cared-for person, but also for carers themselves. Policy development in this area should not undervalue improvements in carer outcomes, even if this creates tensions with improving service user outcomes.

## Annex – the health of carers

Despite the assertion by some that a caring responsibility may have an overall positive result (Evandrou and Glaser 2003), perhaps as a result of the satisfaction derived from the caring role (Young *et al* 2005), there is a great deal of work that suggests the opposite to be the case. Work done by the Princess Royal Trust for Carers, for example, shows that 85 per cent of carers in their sample say that caring had a negative impact on their own health (Keeley and Clarke 2002). Similarly, work undertaken by the Carers' National Association (Henwood 1998) found that more than half of carers reported substantial physical or psychological ill-health of their own while undertaking caring. Such findings are consistent with figures from *Carers 2000*, although the exact figures vary (Maher and Green 2002).

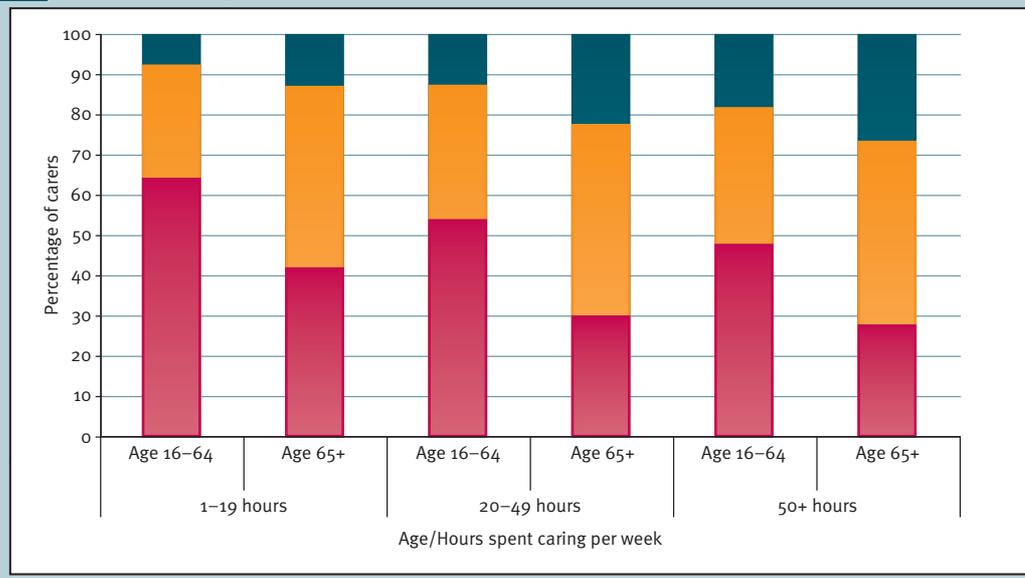
The main self-reported problems experienced by carers that have been attributed to some extent to caring responsibilities include (from Maher and Green 2002):

- feeling tired and stressed (both 20 per cent)
- being short-tempered (17 per cent)
- feeling depressed (14 per cent)
- disturbed/loss of sleep (14 per cent).

This is in addition to other problems and conditions that have been associated with caring, particularly when for long hours and over extended periods (Keeley and Clarke 2002; Hirst 2005). These can include anxiety, depression and psychiatric illness, lowered social functioning, increased susceptibility to physical illness, increased rates of chronic diseases during episodes of caring, general negative impact on physical well-being and even increased mortality as a result of mental or emotional distress, especially in more elderly spousal/partner carers.

The propensity to experience health problems as a result of caring varies with a range of factors, including severity and duration of need and the intensity and nature of caring (such as the number of people being cared for, the number of hours spent caring per week and the stage of the caring relationship). The characteristics of the carer are also relevant (age, sex, residential status, social class and employment status, relationship with care recipient) (Maher and Green 2002; Doran *et al* 2003; Glasser *et al* 2005; Hirst 2005). The effects can be compounded by systemic and external factors, such as a lack of support or respite for carers generally or poor access to health care (Maher and Green 2002; Arksey and Hirst 2005). In addition to this, it has been suggested that it is not only during the caring episode itself that carers present with raised levels of 'carer distress'. Research into psychological distress has found that there is also a continuing adverse effect on psychological well-being at the end of care-giving and beyond, with carers being more susceptible to recurrent distress and negative health effects after the caring responsibility has finished (Hirst 2005).

**9 GENERAL SELF-RATED HEALTH OF CARERS, BY AGE AND NUMBER OF HOURS SPENT CARING PER WEEK, UNITED KINGDOM, 2001**



Source: Based on data from Doran *et al* 2003

**KEY**

- Not good health
- Fairly good health
- Good health

Figure 9 above and Table 15 below illustrate the relationship between the health of carers and various associated factors. These clearly show that the health of carers is damaged.

The impact of these combining factors results in a counterintuitive situation where those groups that are most likely to suffer ill-health as a result of their caring responsibilities receive least support, whereas those who are particularly at risk of a negative impact from

**TABLE 15: PERCENTAGE OF CARERS EXPERIENCING SYMPTOMS OF ILL HEALTH, BY THE NUMBER OF HOURS THEY SPEND CARING PER WEEK AND THEIR RESIDENTIAL STATUS, GREAT BRITAIN, 2000**

Symptoms	Number of hours spent caring per week			Carers with person cared for		Total* (%)
	Under 20 (%)	20-49 (%)	50+ (%)	In the same household (%)	In another household (%)	
Feels tired	12	34	52	34	13	20
Feels depressed	7	27	34	24	9	14
Loss of appetite	1	5	8	5	1	3
Disturbed sleep	7	24	47	31	6	14
General feeling of strain	14	35	40	30	16	20
Physical strain	3	10	24	13	3	7
Short-tempered	11	29	36	28	12	17
Had to see own GP	2	8	17	10	2	4
Other	2	4	2	3	2	2
Health not affected	72	39	28	41	71	61

Source: Based on data from Maher and Green 2002  
 \* Total includes a few people who could not estimate the number of hours.

long hours of care, that is those with the most needy care recipients and those who care for the longest periods, are least likely to be able to access health care when needed.

Research suggests that the extent of the impact on carer health is such that it might be a significant factor in epidemiological analysis, and is a social determinant in the creation of health inequalities (Hirst 2005). It has also been suggested that the adverse effects of caring are avoidable or at the very least could be significantly alleviated through appropriate support. In the current climate of damage limitation, with various initiatives seeking to minimise public involvement in activities that can lead to increased chronic disease rates (smoking, drinking and so on), it is perhaps ironic that here is an activity that has a proven detrimental effect on the health of some individuals, and leads to a need for increased health expenditure for some, that is being actively encouraged without adequate support, particularly for those most at risk. This is a situation that needs to be assessed urgently and action taken accordingly.

# Notes

1. *Carers 2000* (Maher and Green 2002) data look at Britain as a whole, not England specifically. It does not provide exact numbers, but national estimates derived from a nationally representative sample of approximately 14,000 adults living in private households in Britain. Estimates for England have been calculated through use of appropriate data from *Carers 2000*. It should be noted that this derivation will mean discrepancies between the individual countries of Britain will be hidden.
2. Although 2001 Census data are more recent, they are much less detailed and thus offer less scope for analysis. Data from *Carers 2000* (Maher and Green 2002) exclude from its figures: those caring as volunteers or for other organisations and those caring for individuals receiving care in an institution or with a temporary illness or disability (as defined by the respondent).
3. There are some problems with this assumption in this context, however. For example, it is more likely that a care recipient aged over 65 is a parent of the carer than a child (and logically impossible that he or she will be a child under 16!). The number of carers looking after those aged over 65 will therefore be a higher percentage in some relational groups.
4. If there are 6.7 million carers in Britain, then those who care for more than 35 hours per week would number around 1 million. On this basis, with 441,000 claimants, take-up looks low, perhaps only 50 per cent.
5. Interestingly, this is with the exception of ethnic minorities who were deemed to be a special case for cultural reasons, in that it might not be the case that the care was genuinely provided voluntarily.
6. All forms of informal care are not necessarily supported by these options and their variants, however. For example, conditions exist around payment of relatives who live with the care recipient being employed as care assistants (Britain, the Netherlands), or relatives over the age of 65 (Sweden), all of which have associated implications.
7. These arguments are somewhat contradictory, however, in that these traps apply only to people who would be unwilling to provide care without payment (people who would provide with payment would not be trapped)

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