

IN THE KNOW

The importance of information for carers



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SUMMARY

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. There are around 6 million people in the UK with a caring responsibility.

This research found that 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring. For a third of them (32%) it took over 5 years before they recognised they were a carer. These people are often referred to as 'hidden carers'.

Although 50% of respondents felt that they had not missed out on benefits, many did. Of those who did, a staggering 58% had missed out for over 3 years. A similar proportion of carers felt they missed out on practical support. Of those who felt they had missed out, 68% had missed out for over 3 years. Earlier work by Carers UK demonstrated that an estimated £740 million a year in carers' benefits alone could be going unclaimed every year.¹

The research, based on a survey of carers' experiences highlights the cost to carers who remain hidden. It also shows the difference that claiming benefits made to carers' lives. Some bought in extra help, some adapted their homes, others had a bit of extra cash so they could go out, rather than being trapped indoors because they could not afford to take a simple trip out. It is clear that carers use the extra money for vital things to improve their quality of life.

If carers do not get the financial and practical support they need they are vulnerable to a poor quality of life, cutting back and having their health

and well-being seriously affected. Yet reaching these new carers is a difficult task and compounded by the high rate of turnover of carers.

This research also includes a fresh analysis of 2001 Census data. This reveals that each year about 2.2 million people start caring and a similar proportion cease caring. Every year, 37% of the caring population will have started caring in that year and a similar proportion cease caring. This turnover is even higher for those providing more substantial care i.e. 20 hours a week or more, where the movement of carers is around 44%.

We also show that turnover is more pronounced in certain geographic areas, sending a clear signal to planners of local level services that they need to improve how they target information to carers. This report shows how critical it is that information strategies target carers in that crucial first year of caring. The impact for advice and information services is significant because messages need to be constantly repeated and carefully targeted to ensure that carers do not miss out on their entitlements.

1 Caring and Pensioner Poverty, Carers UK 2005

PART ONE: CARERS AND INFORMATION

Background

In many surveys, carers have listed information as a key priority and rate it very highly.² They often use it as a way to have choice and control over their lives, to apply for vital benefits that make a difference to their lives, or to access support services, and to understand how “the system” works.

Our survey of 265 carers looked at why carers ask for information and the sorts of differences that information makes to their lives. It also asked what carers might have missed out on and why this was. A questionnaire was sent out to carers who had asked for information about benefits and entitlements from a special helpline set up by Carers UK for a nationwide carer awareness day in 2005.³ As well as analysing the survey responses we also conducted some follow-up telephone interviews with a sample of carers.

“When my wife left hospital after 4 months, I was told that I would have to have a care assistant half an hour daily and pay approximately £50 per week for this. This was a real burden and worry until Attendance Allowance was paid.”

Importance of information: Why people asked for information

On the whole, people asked for information because they wanted to know about their rights and what help that they could get, or because they thought they would be missing out on benefits. One in six carers wanted more information because they already got help but thought that they might be missing out on something.

All the participants in the survey had received information from Carers UK on benefits and entitlements. As a result of receiving the information:

- one third applied for a carer’s benefit
- one in six either applied for or asked for their Pension Credit to be reviewed

- 21% asked for a carer’s assessment
- 12% said that they had read the information but did not need anything else.

One in every two (51%) said that the information helped them to realise that assistance might be out there if they needed it in the future. They said that the information helped them to plan their lives and make important decisions. At present, they were happy to manage as they were, and, when the time came, they would ask for help or apply for benefits if they needed them. This backs up the findings from an earlier survey on carer’s assessments which found that carers valued knowing about their rights to an assessment, but would use that right when they felt they needed help. They valued knowing where to go for help.

Carers also say that information is not an end in itself, that for there to be real meaning, there had to be something tangible at the end of it. In other words, if a carer providing substantial care, whose health is at risk and who needs support does not get it, the information that led them to ask for support is instantly devalued in the eyes of the carer.

Missing out on benefits

As a result of reading the information, 33% felt that they had missed out on benefits, 50% said that they feel that they had not, and 17% said that they didn’t know. When interviewing carers, it was clear that not knowing was because of the complexity of the benefits system, making it hard for individuals to judge whether they have all their entitlements.

Of those who thought that they had missed out on benefits, 58% thought that they had missed out for over 3 years. As the table shows, a few felt that they had missed out for more than 11 years.

“As we had always lived together I did not claim Carer’s Allowance until 2001. My mum had been getting Attendance Allowance since 1992. I found out that I should have claimed it at the same time in 1992.”

Table 1: How long carers felt they have missed out on benefits for

How long did you miss out on benefits for?	% of total missing out
Up to six months	12
7 to 12 months	7
1-2 years	24
3-4 years	21
5-7 years	17
8-10 years	9
11-15 years	4
16 years	7

Carers who had missed out on benefits felt this had an impact on their pension entitlements, quality of life and health and well-being.

What difference would earlier access to benefits make to carers' lives?

64% of the respondents to the survey said that it would make a great deal of difference, 21% a little difference and 15% no difference at all. Reading carers' comments it is clear that for some, no amount of benefit support would change the fact that a family was coping with an extremely challenging caring situation.

Missing out on a year of Carer's Allowance, for example, at £46.95 per week (2006/7 rates) would mean a loss of income of £2,441 per year and would also mean missing out on contributions towards their pension, at a cost of a minimum of £52 per year for every year lost towards their pension in today's prices.

Carers' comments show a range of impacts on their quality of life:

"Could have used it to turn the heat up a bit and take my husband out."

"I would not have had to leave my husband on his own. Could have paid someone to be with him".

"It would have enabled me to use taxis as my disabled son cannot cope with crowds or noises.

"The Carer's Allowance I now receive has helped my standard of living and my mother's standard of living greatly."

"Help with bills, car tax and insurance. I need a car as I suffer with severe back trouble and cannot walk far."

Missing out on practical support

Practical support is a critical part of supporting carers and protecting their health. This includes equipment, aids, adaptations to the home as well as practical support from care assistants who help wash, dress and move around the person for whom they care. Similar proportions of carers felt that they had missed out on practical support, and 68% felt that they had missed out on practical support for over 3 years.

Table 2: Number of years carers felt they had missed out on practical support

Number of years	% of those feeling that they had missed out
Up to six months	7
7 months to 1 year	1
1-2 years	27
3-4 years	22
5-7 years	18
8-10 years	12
11-15 years	7
16+ years	9

70% said that if they had got this support earlier it would have made a difference, 20% said that it would have made a little difference and 12% no difference at all.

Practical help

Carers' comments showed that practical help was critical in reducing carers' stress and improving their health and emotional well-being. Equipment, for example, helped the older or disabled person be more independent, meaning less input from the carer. Other equipment protected carers' backs but it also helped the carers when washing and bathing the person they care for e.g. a hoist means they do not have to lift someone into the bath. Support from paid care assistants provides carers with a break as well as protecting their health through safer lifting and handling.

For some, getting this extra help meant they could continue to work. As some comments showed, those carers who didn't get the right help had to give up work to care for their relative – a heavy penalty to pay because they did not get the right information and right support at the time.

“It would have helped me to avoid depression and stress”.

“I would not have suffered so much with my back trying to help my husband to the bathroom.”

“My quality of life would have been much better and less stressful. My health and well-being would improve and I could get those jobs done that aren’t touched due to me feeding, cooking, commoding and changing.”

“I could probably have worked longer. I could have gone out instead of staying in 24/7.”

“Could attend training courses, and get promotion. Maybe work over-time and have a night out!”

The importance of carer recognition

When people are first faced with a caring situation it is critical they are given information, advice and support as quickly as possible. One of the problems that advice and information agencies say they face is in reaching so-called ‘hidden carers’ – people who simply don’t recognise what they are doing as being a carer. Because caring is something people do as part and parcel of family life, they sometimes do not see the activity as deserving of a label. Unfortunately, as services are branded as being for carers, without much explanation, many in need miss out because they simply do not think the help applies to them.

These findings therefore show that if you do not recognise the term carer and certainly do not recognise yourself as a carer then you are, for example, less likely to pick up a leaflet in the GP surgery called “information for carers.” This needs to be taken on board by organisations and agencies producing information.

How long was it before you realised you were a carer?

Only half of the respondents responded to this question. However, two-thirds of those (65%) took over a year to realise they were a carer. One third of those who responded to this question (36%) realised within a year that they were a carer, which shows that some information systems are working.

However, Table 3 also shows that a significant proportion of people – nearly one third (32%) did not realise they were a carer for five years or

more. For 4% of the respondents, it took them over 16 years to realise they were a carer. This means that a significant proportion of those people new to caring every year will not necessarily identify themselves as carers, or seek the vital help and benefits that they might be entitled to. We will show that this number could run into hundreds of thousands of people.

Table 3: How many years it was before respondents realised they were a carer

Number of years	% of respondents
Immediately	26
Up to six months	7
6 months to 1 year	3
1-2 years	23
3-4 years	10
5-7 years	14
8-10 years	10
11-15 years	4
16+ years	4

Do you already get benefits?

56% of those who ordered information already got benefits but clearly wanted to know more and wanted updates about benefits changes or practical support they felt they might be missing out on. But a significant proportion, 44%, did not get benefits.

2 You Can Take Him Home Now: carers’ experiences of hospital discharge, Carers National Association, 1998

3 Carers Rights Day 2005 was held on December 5th. This is a national awareness raising day run annually by Carers UK

PART 2: CARER TURNOVER

Background

Every year over 2 million people are faced with new caring responsibilities. This research shows that every year, between 2.17 and 2.29 million people start caring for an adult or child who is chronically sick, disabled or frail and a similar proportion cease caring. In the years studied it varied between 37% and 39% of the total caring population, which is nearly six million, at any given time. Similar proportions, 38% to 40% cease caring every year. The overall population of carers over a five year time period has remained fairly static although the numbers of carers providing significant amounts of care (more than 20 hours) has increased since 1993.

This part of the research builds on work by Michael Hirst based on the British Household Panel Survey⁴ and combines information from the Census 2001, to show the potential turnover of carers across the UK, by local authority or Health and Social Services Trust in Northern Ireland.

Turnover of carers

Table 4 below shows the huge volume of change of carers across the UK who start and stop caring each year. The turnover of carers is even higher amongst those who provide more substantial care

i.e. 20 hours per week or more, around 44% of carers within those groups.

The implications of these figures are significant as services, whether public, private or voluntary, need to plan for this constant change. The combination of high turnover and the 'hidden carer' effect may go some way to explaining why an estimated £740 million in carers' benefits alone go unclaimed every year.⁵ Previous research has shown that despite being given information about benefits, carers were still unclear about entitlements. Others were put off claiming because of complex rules and the intrusion of means testing.⁶ Some carers, of course, will choose not to claim benefits.

Turnover rates – implications for services and employers

Appendix 1 shows the turnover of carers by local authority. These figures effectively show how many carers a local authority might have to reach to ensure that they have the information they need to care safely, as well as accessing all their rights and entitlements. These turnover rates are equally relevant to GP surgeries, Primary Care Trusts in England or Local Health Boards in Wales, for example.

Table 4: Turnover of carers every year

	Total no. of carers. Source Census 2001	No. of people starting caring every year	Total no. of carers providing 20 hours of care per week or more. Source, Census 2001	No. of people providing over 20 hours of care per week who begin caring every year
England	4,877,060	1,804,512	1,529,529	672,993
Scotland	481,579	178,184	175,979	77,431
Wales	340,745	126,076	129,833	57,127
Northern Ireland	185,066	68,474	74,656	32,849
UK	5,884,450	2,177,247	1,909,997	840,400

Table 5: Number of carers over 60, numbers eligible for Pension Credit and those new every year entitled to Pension Credit.

	Number of carers over 60	Number of carers eligible for Pension Credit ^a	New carers every year eligible for Pension Credit
England	1,340,285	509,308	188,443
Scotland	110,299	40,811	15,096
Wales	93,381	34,551	12,783
NI	33,217	12,290	4,547
UK	1,577,182	596,960	220,875

The work by Hirst also suggested that a typical local Benefits Agency (now Jobcentre Plus or Pensions Service) would have to deal with around 1,200 new carers every year (based on the Benefits Agency geographical areas in 1999).⁷ Since 1999, Government has significantly re-organised the Benefits Agency and ways in which people claim. However, these figures are nevertheless useful targets if Government is considering information dissemination to improve awareness and take-up of benefits. More in-depth studies could help Jobcentre Plus to plan how many carers are likely to need return-to-work advice once a period of caring has ceased, for example.

Tailoring and targeting information

The following example looks at older carers and entitlements to Pension Credit and shows that as many as 220,000 older carers may become entitled to Pension Credit every year. This demonstrates the degree to which services have to respond to need and repeat new messages.

The situation of older carers in relation to Pension Credit also illustrates the complex job that information services have in trying to target messages to ensure that carers do not miss out. On top of the difficulty of carers recognising that they are carers, is the complexity of the benefit rules. In this case, older carers will need advice on claiming Carer's Allowance to gain underlying entitlement and then a review of their Pension Credit as to whether they would be eligible for the Carer Addition – a top up to Pension Credit. It might be that some of these carers were turned down for Pension Credit before, but with underlying entitlement, they might become eligible. As this example demonstrates the system is complicated to understand without the support of an expert adviser. It also

demonstrates the need to review how these overlapping benefit rules work and whether there is an easier way of carers accessing these entitlements.

All other information service providers, whether voluntary, public or private, will need to constantly repeat messages if new carers are to receive information at the right time.

As well as recognising the implications of the turnover of carers in the provision of information and practical services, organisations and service providers also have to recognise that there are several groups who will face additional barriers in accessing information. They include:

- carers whose first language is not English
- carers whose culture and understanding of the benefits and rights system is different
- carers living in rural areas
- carers with disabilities, including learning disabilities
- carers who have low literacy

It is vital that information systems respond to the needs of these groups and then services are designed around their needs. Carers UK has brought together as much relevant material as possible in accessible formats and in different languages which refers to carers. However, this also identifies a need to ensure that there is more central co-ordination of information.

Employers and turnover of carers within staff

Employers should also take an interest in the turnover of carers, and can easily estimate how

many employees might become carers in a given year. For example, in a business of 1,000 employees, 120 staff will be a carer at any given time. Every year, that business could expect around 44 staff to become carers. This should help businesses to plan for the new right to request flexible working for carers, under the Work and Families Act 2006, due to be implemented in April 2007. Work by Carers UK's Action for Carers and Employment partnership, has demonstrated business benefits in supporting carers in the workplace.⁹

Research has shown that when caring reaches 20 hours a week, a carer's ability to work starts to be affected.¹⁰ Similarly when caring starts to reach these levels, a carer's health is more likely to suffer, particularly if they care for 50 or more hours per week. These carers are up to three times more likely to suffer ill-health compared to non-carers.¹¹ It is critical that strategies target these carers.

Some carers start with heavy caring responsibilities overnight, others build up gradually, for example, they are caring for someone with Alzheimer's Disease.

Targeting areas of high turnover

Areas of highest turnover of carers are, naturally, those which proportionately have more carers, such as Neath Port Talbot in Wales. The actual turnover rates will probably vary in every local authority area according to the age of the carer, whether they are living with the person they care for, the number of hours they provide, gender, work status, etc. Work carried out by Hirst shows that turnover is higher where carers are living with the person they are caring for.¹² Women, for example, are statistically more likely to be caring for someone during their working life i.e. they have a 50:50 chance of caring for more than 20 hours by the time they are 59. Men on the other hand have a similar chance by the time they are 74.¹³ However, a great deal of work by local authority would have to be done, including further work on the British Household Panel Survey, to deliver this more detailed information for a local area. It would take a considerable investment of funds to do so.

It is important, however, that local authorities and other service providers look at this work and plan for its implications.

Ceasing caring

Although this work has focussed primarily on those beginning caring, those ceasing caring can be just as vulnerable to change. If a carer provides significant care, they are likely to be financially affected, give up work to care, become socially isolated and their health can be affected. One carer, for example, cared for her mother and then her husband, who had a degenerative disease. After giving up her job and caring for him for 12 years, her health had deteriorated, she was claiming Incapacity Benefit, she was in receipt of Income Support, her social networks had reduced considerably, she felt there was no prospect of work. Once her caring responsibilities ended she needed considerable support to rebuild her life.

It is vital that service and information providers also plan for when caring comes to an end. For example, if a carer can be kept in work longer, their entry back to the labour market will be made easier when they cease caring. Similarly, pre-vocational and vocational training has an important role to play, as do bereavement counsellors and social networks that help carers to move beyond their networks of caring from social exclusion to social inclusion.

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- 4 Informal Carers – A Moving Target?, M Hirst, Cash & Care 23, Social Policy Research Unit, University of York, 1999
 - 5 Caring and Pensioner Poverty, Carers UK 2005 and Older Carers, L Buckner and S Yeandle, Sheffield Hallam University, published by Carers UK, 2005.
 - 6 Ibid
 - 7 Informal Carers, op cit
 - 8 Older carers, Carers UK 2005
 - 9 Who Cares Wins, the Social and Business Benefits of Caring, S Yeandle and L Buckner, Sheffield Hallam University, 2006, Carers UK
 - 10 Security in retirement: towards a new pensions system, May 2006, Department for Work and Pensions.
 - 11 In Poor Health, the impact of caring on health, Carers UK, 2004
 - 12 Informal Carers – A moving target?, M Hirst, Cash & Care 23, Social Policy Research Unit, University of York, 1999
 - 13 Informal care over time, M Hirst, Benefits: Social Security Research, Policy and Practice, 28, pp 9-12, 2000

PART 3: CONCLUSIONS AND RECOMMENDATIONS

With the high turnover of carers and the risks to carers in terms of their health and well-being, this report shows how critical it is that information strategies target carers in that crucial first year of caring. This means engaging with carers where they are likely to visit and request advice. GPs and hospital staff, for example, are likely to be a first port of call for medical advice. Carers in work may tell their line manager or human resources department. Others may seek help from their local benefits office. Carers are more likely to have contact at these points far sooner than with social services or the voluntary sector.

Yet, this research also shows that carers may not get the information they need for years. It is vital that other key professionals, such as social workers, help by signposting carers to sources of advice, as well as ensuring that assumptions are not made about longer-term carers knowing all about their rights and entitlements. All information and advice strategies need to constantly repeat simple messages to ensure that carers do not miss out. Equally they need strategies to plan to help those carers who cease caring.

Messages for information providers

It is clear from this data that the vast turnover of carers has different implications for different areas where there are more carers. It also has implications for organisations who run services to disabled people and carers in terms of the types of information that they give out and the messages that they need to get across. This includes information for when carers cease caring.

Government agencies which promote information to people needing to claim entitlements must plan better for this change in the population of carers. Those new to caring need different information to those leaving caring, who may want support to return to work, for example. Health bodies and local authorities also need to consider how this fits into their information strategies and delivery of practical support.

In England, for example, Local Area Agreements should be spelling out strategies to help deal with the enormous turnover of carers. For example, information strategies to help those new to caring to access the financial and practical support that they need. There also need to be planning and support strategies for carers who have been providing care for years or perhaps over an intense period, who will find it hard to adjust when they are no longer caring. They will need pre-vocational support, often to help them on the pathway back to work. Support services need to plan for this type of intake of new services.

Service level agreements that Primary Care Trusts or local authorities make with voluntary organisations who provide support to carers should also be looking at these issues as well as building these statistics into their information strategies and their health improvement plans.

Messages for care service providers

It is also critical that practical services plan around this turnover too, expecting movement in and out of caring, but also accepting that a proportion of carers will be caring long term. Those caring long term will have very particular needs as the longer they provide care, the more likely it is that they will be on an increasingly low income, have poorer health and give up work to care.

Care service providers also need to take a longer term view realising that some carers will need different support when they cease caring. Care service providers have a critical role in preventing health breakdown, in keeping social contacts for carers and in helping carers to continue working.

Messages for national government

These figures also touch on Government policy in terms of pension planning, information campaigns around benefits and pensions awareness, the construction of the benefits system around carers ability to move in and out of work whilst still caring, and support for those for whom caring is a long term commitment.

Given in 2007 Government's forthcoming Comprehensive Spending Review, it is critical that Government looks not only at these issues, but also at the role of care services in preventing many of the negative aspects of caring. This will be vital for those carers caring long term and will help to ease the transition for those ceasing caring back to work and to lives that most people expect to have but from which carers have been excluded.

For Government, it is important that they enhance the development of understanding and knowledge about the UK's population of carers. It is vital that a question on carers is part of the next Census. They must also ensure that Government policy is tailored to carers' needs and focuses on areas of greatest need and largest disparity between carers and non-carers.

Recommendations:

- It is critical that Government includes the same question on carers in the 2011 Census as it did in 2001. Census information is vital for local authorities, NHS organisations, voluntary and private sector organisations to be able to successfully plan the delivery of services.
- That Government look at the critical role of social care in its forthcoming Comprehensive Spending Review.
- Local authorities' and health and social services trusts, in their strategies for carers, should have an explicit recognition that there is a new cohort of carers every year and demonstrate practical steps in which they will seek to address this turnover of carers. They also need to address the fact that caring will cease for some carers and plan to mitigate the negative effects of caring.
- In England, Local Area Agreements must have explicit strategies to address these issues.
- Information and advice agencies should plan for both those people new to caring every year, but also to reach those who might have been caring for years unaware of their benefits and entitlements.
- Information and advice agencies also need to plan for advising carers who are at the end of caring, helping them to return to work or plan for the future.
- Employers should ensure good implementation of the new Work and Families Act 2006 which will give carers a right to request flexible working.
- Employers also have a critical role to play in signposting carers towards appropriate information via their intranets, notice boards, staff support mechanisms, etc.
- Government should fund information and awareness campaigns and, in particular, fund a national helpline for carers.
- Government should carry out a major review of purpose and design of carers benefits to better reflect the different needs of those moving in and out of care/work and those caring long term.
- The public has a role to play in helping carers to recognise themselves as carers and seek help and entitlements by signposting relatives, friends and colleagues to appropriate forms of support.
- The social care industry must reduce the confusion around the term carer by using clear language that distinguishes between paid careworkers and carers – who care, unpaid, for family, relatives and friends who have disabilities, chronic illness or frailty. This would help carers to access the support they need.

APPENDIX 1

Turnover of carers by nation and local authority based on Census 2001 statistics

	No. of carers	New carers every year
UK	5884450	2177247
England	4877060	1804512
Wales	340745	126076
Scotland	481579	178184
NI	185066	68474
ENGLAND		
NORTH EAST	276593	102339
Darlington UA	10064	3724
Hartlepool UA	9853	3646
Middlesborough UA	14605	5404
Redcar and Cleveland UA	16107	5960
Stockton-on-Tees UA	18993	7027
Durham	57225	21173
Chester-le-Street	6166	2281
Derwentside	9886	3658
Durham	9247	3421
Easington	11964	4427
Sedgefield	10258	3795
Teesdale	2735	1012
Wear Valley	6969	2579
Northumberland	33609	12435
Alnwick	3033	1122
Berwick-upon-Tweed	2673	989
Blyth Valley	8882	3286
Castle Morpeth	5677	2100
Tynedale	6129	2268
Wansbeck	7215	2670
Tyne and Wear (Met county)	116137	42971
Gateshead	21133	7819
Newcastle upon tyne	26267	9719
North Tyneside	21002	7771
South Tyneside	15871	5872
Sunderland	31864	11790
NORTH WEST	724802	268177
Blackburn with Darwen UA	13991	5177
Blackpool UA	15443	5714
Halton UA	13528	5005
Warrington UA	19976	7391
Cheshire	71675	26520
Chester	12449	4606
Congleton	9533	3527
Crewe and Nantwich	11490	4251
Ellesmere Port and Neston	9338	3455
Macclesfield	15681	5802
Vale Royal	13184	4878

	No. of carers	New carers every year
Cumbria	51702	19130
Allerdale	9908	3666
Barrow-in-Furness	8667	3207
Carlisle	10012	3704
Copeland	7218	2671
Eden	4818	1783
South Lakeland	11079	4099
Greater Manchester (Met County)	257739	95363
Bolton	28385	10502
Bury	19231	7115
Manchester	34476	12756
Oldham	23556	8716
Rochdale	21988	8136
Salford	22445	8305
Stockport	30185	11168
Tameside	22240	8229
Trafford	21346	7898
Wigan	33887	12538
Lancashire	123591	45729
Burnley	9756	3610
Chorley	10925	4042
Fylde	8146	3014
Hyndburn	8900	3293
Lancaster	13593	5029
Pendle	9819	3633
Preston	13086	4842
Ribble Valley	5865	2170
Rossendale	7090	2623
South Ribble	11450	4237
West Lancashire	12471	4614
Wyre	12490	4621
Merseyside (Met County)	157157	58148
Knowsley	17360	6423
Liverpool	48123	17806
St Helens	21519	7962
Sefton	32701	12099
Wirral	37454	13858
YORKS AND THE HUMBER	518211	191738
East Riding of Yorkshire UA	32765	12123
City of Kingston upon Hull UA	22982	8503
North East Lincolnshire UA	15335	5674
North Lincolnshire UA	15952	5902
York UA	17009	6293
North Yorkshire	56529	20916
Craven	5689	2105
Hambleton	8358	3092
Harrogate	14524	5374
Richmondshire	4011	1484
Ryedale	5095	1885
Scarborough	11304	4182
Selby	7548	2793
South Yorkshire (Met County)	144395	53426
Barnsley	26109	9660
Doncaster	31944	11819
Rotherham	30284	11205
Sheffield	56058	20741

	No. of carers	New carers every year
West Yorkshire (Met County)	213244	78900
Bradford	47980	17753
Calderdale	19748	7307
Kirklees	39994	14798
Leeds	70446	26065
Wakefield	35076	12978
EAST MIDLANDS	435741	161224
Derby UA	23733	8781
Leicester UA	26868	9941
Nottingham UA	24129	8928
Rutland UA	3339	1235
Derbyshire	86436	31981
Amber Valley	13730	5080
Bolsover	9087	3362
Chesterfield	12134	4490
Derbyshire Dales	8160	3019
Erewash	11895	4401
High Peak	9710	3593
North East Derbyshire	12574	4652
South Derbyshire	9146	3384
Leicestershire	63387	23453
Blaby	9535	3528
Charnwood	15230	5635
Harborough	7679	2841
Hinckley and Bosworth	10990	4066
Melton	4766	1763
North West Leicsterhsire	9358	3462
Oadby and Wigston	5829	2157
Lincolnshire	65633	24284
Boston	5654	2092
East Lindsey	14846	5493
Lincoln	7834	2899
North Kesteven	9612	3556
South Holland	7809	2889
South Kesteven	11322	4189
West Lindsey	8556	3166
Northamptonshire	59035	21843
Corby	5142	1903
Daventry	6893	2550
East Northamptonshire	7021	2598
Kettering	8199	3034
Northampton	17297	6400
South Northamptonshire	7406	2740
Wellingborough	7077	2618
Nottinghamshire	83181	30777
Ashfield	12647	4679
Bassetlaw	12357	4572
Broxtowe	11638	4306
Gedling	12460	4610
Mansfield	11682	4322
Newark and Sherwood	11707	4332
Rushcliffe	10690	3955

	No. of carers	New carers every year
WEST MIDLANDS	558421	206616
County of Herefordshire UA	17577	6503
Stoke-on-Trent UA	26870	9942
Telford and Wrekin UA	15723	5818
Shropshire	30055	11120
Bridgnorth	5726	2119
North Shropshire	5968	2208
Oswestry	3922	1451
Shrewsbury and Atcham	9896	3662
South Shropshire	4543	1681
Staffordshire	89734	33202
Cannock Chase	10118	3744
East Staffordshire	10354	3831
Lichfield	10298	3810
Newcastle-under-Lyme	14111	5221
South Staffordshire	12741	4714
Stafford	13279	4913
Staffordshire Moorlands	11359	4203
Tamworth	7474	2765
Warwickshire	53221	19692
North Warwickshire	7070	2616
Nuneaton and Bedworth	13212	4888
Rugby	9059	3352
Stratford-on-Avon	11532	4267
Warwick	12348	4569
West Midlands (Met County)	268077	99188
Birmingham	98279	36363
Coventry	30047	11117
Dudley	35030	12961
Sandwell	30086	11132
Solihull	20987	7765
Walsall	27941	10338
Wolverhampton	25707	9512
Worcestershire	57164	21151
Bromsgrove	10152	3756
Malvern Hills	8241	3049
Redditch	7867	2911
Worcester	8680	3212
Wychavon	11752	4348
Wyre Forest	10472	3875
EAST	520209	192477
Luton UA	16092	5954
Peterborough UA	14699	5439
Southend-on-Sea UA	15973	5910
Thurrock UA	13338	4935
Bedfordshire	35869	13272
Bedford	14482	5358
Mid-Bedfordshire	11143	4123
South Bedfordshire	10244	3790
Cambridgeshire	50673	18749
Cambridge	8901	3293
East Cambridgeshire	7026	2600
Fenland	8159	3019
Huntingdonshire	13750	5088
South Cambridgeshire	12837	4750

	No. of carers	New carers every year
Essex	129236	47817
Basildon	15685	5803
Braintree	12396	4587
Brentwood	6902	2554
Castle Point	8998	3329
Chelmsford	15009	5553
Colchester	14516	5371
Epping Forest	12247	4531
Harlow	7022	2598
Maldon	6211	2298
Rochford	8022	2968
Tendring	15581	5765
Uttlesford	6647	2459
Hertfordshire	96190	35590
Broxbourne	7923	2932
Dacorum	13057	4831
East Hertfordshire	11482	4248
Hertsmere	8890	3289
North Hertfordshire	11073	4097
St Albans	12249	4532
Stevenage	7032	2602
Three Rivers	8129	3008
Watford	6880	2546
Welwyn Hatfield	9475	3506
Norfolk	81653	30212
Breckland	11755	4349
Broadland	12628	4672
Great Yarmouth	9647	3569
King's Lynn and West Norfolk	14498	5364
North Norfolk	10720	3966
Norwich	10760	3981
South Norfolk	11645	4309
Suffolk	66486	24600
Babergh	8662	3205
Forest Heath	4335	1604
Ipswich	11286	4176
Mid Suffolk	8637	3196
St Edmundsbury	9115	3373
Suffolk Coastal	12377	4579
Waveney	12074	4467
LONDON	609890	225659
Inner London	207976	76951
Camden	15528	5745
City of London	598	221
Hackney	15347	5678
Hammersmith and Fulham	11600	4292
Haringey	15967	5908
Islington	13726	5079
Kensington and Chelsea	11200	4144
Lambeth	18536	6858
Lewisham	19675	7280
Newham	20663	7645
Southwark	18515	6851
Tower Hamlets	16797	6215
Wandsworth	17217	6370
Westminster	12607	4665

	No. of carers	New carers every year
Outer London	401914	148708
Barking and Dagenham	15920	5890
Barnet	28171	10423
Bexley	21422	7926
Brent	22900	8473
Bromley	28386	10503
Croydon	29496	10914
Ealing	25736	9522
Enfield	24391	9025
Greenwich	18797	6955
Harrow	20550	7604
Havering	23253	8604
Hillingdon	23118	8554
Hounslow	18921	7001
Kingston upon Thames	12345	4568
Merton	15141	5602
Redbridge	23848	8824
Richmond upon Thames	14570	5391
Sutton	16126	5967
Waltham Forest	18823	6965
SOUTH EAST	737751	272968
Bracknell Forest UA	8278	3063
Brighton and Hove UA	21803	8067
Isle of Wight UA	14364	5315
Medway UA	21491	7952
Milton Keynes UA	17400	6438
Portsmouth UA	14983	5544
Reading UA	10956	4054
Slough UA	10187	3769
Southampton UA	18155	6717
West Berkshire UA	12116	4483
Windsor and Maidenhead UA	11501	4255
Wokingham UA	12287	4546
Buckinghamshire	43821	16214
Aylesbury Vale	14351	5310
Chiltern	8765	3243
South Bucks	6004	2221
Wycombe	14701	5439
East Sussex	50993	18867
Eastbourne	8767	3244
Hastings	8635	3195
Lewes	9695	3587
Rother	9553	3535
Wealden	14343	5307
Hampshire	113835	42119
Basingstoke and Deane	12670	4688
East Hampshire	10207	3777
Eastleigh	10759	3981
Fareham	10081	3730
Gosport	6545	2422
Hart	7021	2598
Havant	11490	4251
New Forest	17697	6548
Rushmoor	6938	2567
Test Valley	10327	3821
Winchester	10100	3737

	No. of carers	New carers every year
Kent	128524	47554
Ashford	9705	3591
Canterbury	13375	4949
Dartford	7746	2866
Dover	10787	3991
Gravesham	9048	3348
Maidstone	13300	4921
Sevenoaks	10890	4029
Shepway	10015	3706
Swale	11344	4197
Thanet	13410	4962
Tonbridge and Malling	9721	3597
Tunbridge Wells	9183	3398
Oxfordshire	53435	19771
Cherwell	11423	4227
Oxford	10522	3893
South Oxfordshire	11802	4367
Vale of White Horse	10865	4020
West Oxfordshire	8823	3265
Surrey	99811	36930
Elmbridge	11060	4092
Epsom and Ewell	6597	2441
Guildford	11962	4426
Mole Valley	8274	3061
Reigate and Banstead	11878	4395
Runnymede	7024	2599
Spelthorn	8766	3243
Surrey Heath	7052	2609
Tandridge	7746	2866
Waverley	11291	4178
Woking	8161	3020
West Sussex	73811	27310
Adur	6169	2283
Arun	14787	5471
Chichester	10728	3969
Crawley	8846	3273
Horsham	11641	4307
Mid Sussex	12116	4483
Worthing	9524	3524
SOUTH WEST	495442	183314
Bath and North East Somerset UA	16225	6003
Bournemouth UA	15450	5717
City of Bristol UA	35344	13077
North Somerset UA	19483	7209
Plymouth UA	24058	8901
Poole UA	14387	5323
South Gloucestershire UA	24092	8914
Swindon UA	15745	5826
Torbay UA	13881	5136
Cornwall and the Isles of Scilly	55791	20643
Caradon	8839	3270
Carrick	9736	3602
Kerrier	10540	3900
North Cornwall	8866	3280
Penwith	7266	2688
Restormel	10372	3838
Isles of Scilly	172	64

	No. of carers	New carers every year
Devon	72969	26999
East Devon	13764	5093
Exeter	9896	3662
Mid Devon	6942	2569
North Devon	8993	3327
South Hams	9109	3370
Teignbridge	12785	4730
Torridge	6249	2312
West Devon	5231	1935
Dorset	42172	15604
Christchurch	5184	1918
East Dorset	9336	3454
North Dorset	5948	2201
Purbeck	4835	1789
West Dorset	10068	3725
Weymouth and Portland	6801	2516
Gloucestershire	55700	20609
Cheltenham	9828	3636
Cotswold	7691	2846
Forest of Dean	8516	3151
Gloucester	10413	3853
Stroud	11490	4251
Tewkesbury	7762	2872
Somerset	50304	18612
Mendip	10029	3711
Sedgemoor	10902	4034
South Somerset	15303	5662
Taunton Deane	10251	3793
West Somerset	3819	1413
Wiltshire	39886	14758
Kennet	6684	2473
North Wiltshire	11392	4215
Salisbury	10781	3989
West Wiltshire	11059	4092
WALES	340745	126076
Blaenau Gwent	8751	3238
Bridgend	16189	5990
Caerphilly	20856	7717
Cardiff	31172	11534
Carmarthenshire	21840	8081
Ceredigion	7811	2890
Conwy	12316	4557
Denbighshire	10677	3950
Flintshire	16451	6087
Gwynedd	11247	4161
Isle of Anglesey	7220	2671
Merthyr Tydfil	7042	2606
Monmouthshire	9608	3555
Neath Port Talbot	18923	7002
Newport	15360	5683
Pembrokeshire	13583	5026
Powys	14118	5224
Rhondda Cynon Taf	28998	10729
Swansea	28355	10491
Torfaen	11504	4256
The Vale of Glamorgan	13849	5124
Wrexham	14875	5504

SCOTLAND	481579	178184
Aberdeen	16758	6200
Aberdeenshire	17009	6293
Angus	9492	3512
Argyll and Bute	8509	3148
Clackmannanshire	4812	1780
Dumfries and Galloway	14043	5196
Dundee	13942	5159
East Ayrshire	12454	4608
East Dumbartonshire	11656	4313
East Lothian	8830	3267
East Renfrewshire	9206	3406
Edinburgh	38876	14384
Eilean Siar	2813	1041
Falkirk	14914	5518
Fife	33808	12509
Glasgow	56611	20946
Highland	18505	6847
Inverclyde	8167	3022
Midlothian	8187	3029
Moray	6835	2529
North Ayrshire	13486	4990
North Lanarkshire	33219	12291
Orkney Islands	1706	631
Perth and Kinross	12134	4490
Renfrewshire	18031	6671
Scottish Borders	9172	3394
Shetland	1968	728
South Ayrshire	11385	4212
South Lanarkshire	31896	11802
Stirling	8129	3008
West Dumbartonshire	9879	3655
West Lothian	15147	5604

NORTHERN IRELAND	185066	68474
Antrim	4815	1782
Ards	8987	3325
Armagh	5650	2091
Ballymena	5664	2096
Ballymoney	2526	935
Banbridge	4439	1642
Belfast	32706	12101
Carrickfergus	4285	1585
Castlereagh	8499	3145
Coleraine	5396	1997
Cookstown	3389	1254
Crigavon	8876	3284
Derry	11093	4104
Down	7019	2597
Dungannon	5059	1872
Fermanagh	5711	2113
Larne	3492	1292
Limavady	2904	1074
Lisburn	12409	4591
Magherafelt	3791	1403
Moyle	1642	608
Newry and Mourne	9085	3361
Newtownabbey	9259	3426
North Down	9688	3585
Omagh	4803	1777
Strabane	3879	1435

APPENDIX 2

Respondents' profiles

- A slight majority (53%) of respondents were aged over 60, and 47% were of working age. Of the people the people whom they looked after, the majority were aged over 60 i.e. 74% and 26% under the age of 60.
- 25% were male, 75% female and the majority (95%), were White British or White European. 5% had been caring for less than a year. However, a large proportion, 65%, had been caring for 5 years or longer. 16% of respondents had been caring for over 16 years.
- 23% of all respondents were in paid employment. 39% under 60 were in paid employment, compared to 12% of those over 60. Of those under 60, 64% were in part-time employment.

Carers UK is the voice of carers

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination.

Carers UK is an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Carers UK is here to improve carers' lives.

- We fight for equality for carers. We want carers to have the same right as everyone else to an ordinary life – a fair level of income, adequate support to protect their health and well being and access to the world of work, leisure and education
- We seek to empower carers. We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of health and social care services.

Carers UK achieves this by:

- campaigning for the changes that make a real difference for carers
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision-makers
- gathering hard evidence about what needs to change
- transforming the understanding of caring so that carers are valued and not discriminated against

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