



Facts about carers

June 2009

What is a carer?

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.

How many people are carers?

The latest figures on carers are from the 2001 Census. This showed that there are nearly 6 million carers in the UK. This is 10% of the total population, or approximately 12% of the adult population.

There are 1.9 million people caring for more than 20 hours per week and 1.25 million care for more than 50 hours per week.

Statistics about carers in England, Wales, Scotland and Northern Ireland. Numbers of carers, all ages. (Source, Census 2001)

	Numbers of carers	% of total population (all ages)	Numbers of carers providing 50+ hrs care per week	% of all carers providing 50+ hrs care per week
England	4,877,060	10	998,732	20
Northern Ireland	185,086	11	46,912	25
Scotland	481,579	10	115,674	24
Wales	340,745	11	89,604	26
UK Total	5,884,450	10	1,250,922	21

In Scotland, a statistical profile carried out in 2002 found that there were an estimated 668,200 carers in Scotland. This represents 12% of the population. Of these carers, 62% were women and 38% were men.¹



In a report from the Health and Social Wellbeing Survey 1997 in Northern Ireland a random sample of 3,520 addresses revealed that 18% of respondents were carers, 6% of whom provide care for 20 or more hours a week. Just under a quarter of respondents aged 45 to 64 provided care.ⁱⁱ

Who are carers?

The 2001 Census shows that women are more likely to be carers than men. Across the UK there are 3,400,000 female carers (58% of carers) and 2,460,000 male carers (42%).

Women have a 50:50 chance of providing care by the time they are 59; compared with men who have the same chance by the time they are 75 years old. Women are more likely to give up work in order to care (*Source: It could be you, Carers UK 2000*).

Most carers (5.7 million) are aged over 18 and the peak age for caring is 50 to 59. More than one in five people aged 50-59 (1.5 million across the UK) are providing some unpaid care. One in four women in this age group is providing some care compared with 18% of men. This compares with 6% of adults aged 18 to 34, 12.5% aged 35 to 44, and 11.5% aged 65 or over.

Caring varies between ethnic groups. Bangladeshi and Pakistani men and women are three times more likely to provide care compared with their white British counterparts (*Source: Who cares wins, statistical analysis of the Census Carers UK, 2001*).

Figures from the 2001 Census indicate that there are 174,995 young people under the age of 18 who provide care, 13,029 of these provide care for 50 hours or more per week. The vast majority (85%) of all children providing care are caring for 1 to 19 hours per week. This is a large category which masks some important issues. For example, there is a huge difference between providing a couple of hours support to a disabled brother or sister and a son or daughter providing the sole support for a lone parent with severe mental illness. The impact on the child could be very different.

Impacts of caring

Financial

The financial costs of caring can be significant. Research by Carers UKⁱⁱⁱ found that 72% of carers were worse off financially as a result of becoming carers. The reasons cited for this include the additional costs of disability, giving up work to care, the inadequacy of disability benefits and the charges for services. Carers can face higher bills than the rest of the population (including extra heating, laundry and transport costs) and many do not get support from social services, meaning that they have to pay for care themselves. Carers UK's most recent research^{iv} reveals that nearly two thirds are spending their own income or savings to pay for care for the person they look after. The same research also found carers reporting financial hardship in a number of areas. More than half (54%) were in debt as a result of caring. Three-quarters struggled to pay essential bills (74%) and could not afford repairs to their house (78%). Half of all carers are cutting back on food just to make ends meet (52%). 32% of those paying rent or a mortgage say they cannot afford to pay it.



Health

The impact of caring can be detrimental to the health of carers. Carers UK's analysis of the 2001 Census findings, *In poor health*^v, found that those caring for 50 hours a week or more are twice as likely to be in poor health as those not caring (21% against 11%).

This difference is especially marked amongst younger people. In the 18-25 age group those providing 50 hours care or more per week are three times as likely to be in 'not good' health as people of that age group not providing care (8% against 2.5%). This backs up earlier research, including a 2002 study, which found that carers were over twice as likely to have mental health problems if they provided substantial care; 27% of those providing over 20 hours a week had mental health problems compared to 13% of those providing less than 20 hours of care.^{vi}

Analysis of the Census also indicates that carers providing high levels of care are twice as likely to be 'permanently sick or disabled' as those not caring. Altogether 316,000 people in the UK who provide care describe themselves as 'permanently sick or disabled', of these 124,900 care for 50 or more hours per week.

Those providing care over a long period of time are at particular risk of poor health and both mental and physical health are likely to deteriorate the longer the carer has been caring. Analysis of the British Household Panel Survey^{vii} has demonstrated that the health of carers is more likely to deteriorate over time than the health of non-carers and many of the detrimental changes can be attributed to the caring role. Research by Michael Hirst^{viii} for the University of York indicates that the physical health of carers is more likely to decline after the first year of caring. The research also identifies spouse carers and mothers looking after a disabled child as being most at risk of psychological distress and the period immediately after caring ends as a period where ill health is likely to increase.

Other factors contributing to poor health amongst carers are low incomes and lack of breaks. Research by Carers UK found 62% worried about their finances and 53% believed this had an effect on their health.^{ix} Other research has found that those not receiving a break were far more likely to suffer from mental health problems, 36% compared to 17% of those carers getting a break.^x And many carers report that they are forced to ignore their own health because of a lack of alternative care and the absence of emergency planning. Research by Carers UK includes cases of carers discharging themselves from hospital because of an absence of alternative care.^{xi}

Further details on carers' health are available in our policy briefing on Carers Health, available on our website: www.carersuk.org.



Carers in the workplace

The 2001 Census found that 3 million people combine work with caring responsibilities for a disabled, ill or frail relative or friend. This is roughly one in eight workers in the UK. Of these, over 2 million carers work full time and 1 million part-time. Male carers are more likely to be in work than females, six out of ten male carers work, and 90% of these work full-time.

Eight out of ten carers are of working age, ie aged between 16 and 65. An astonishing 400,000 people in the UK combine full-time work with caring for 20 hours a week or more, of these 200,000 are caring for 50 hours per week or more.^{xii}

Combining paid work and looking after a relative or friend causes stress and can lead to carers giving up work. An Equal Opportunities Commission survey in 2004 showed that one in five carers had given up work or turned down a job because of their caring responsibilities.

Carers UK's Real Change Not Short Change survey, which had a higher proportion of heavy end and older carers, found that more than half (54%) had given up work to care. Many had retired early due to their caring responsibilities – an average of 8 years early.

Nearly nine in ten (87%) working age carers looking after their partner had no-one in the household in paid work.

The carers who responded to this survey had lost an average of £11,000 per year in earnings because of giving up work, cutting their hours or taking a more junior job.

We also know that working carers are more likely to be unqualified, and less likely to hold university degrees, than other people in employment^{xiii}.

Working carers of both sexes are much less likely to be in higher level jobs. Almost 45% of men and 55% of women who are in paid work and caring for 20 or more hours a week are in elementary occupations, "process plant and machine operative jobs" or in sales, customer services or personal services^{xiv}.

Another barrier to carers combining caring with paid work is a lack of care services. A major research study of working carers found that only a quarter of them felt they had adequate support from formal services to enable them to combine work and care. Furthermore between 40 and 50 per cent of working carers say that a lack of flexibility and sensitivity in the delivery of services is hampering them. The majority of working carers say they need at least one type of formal service which they are not currently receiving^{xv}.



Carers and social exclusion

Carers face social exclusion due to the isolation of caring and discrimination against them by service providers.

A major issue raised by carers is how inflexible or unreliable transport services (ie late running, strikes, cancellations or diversions without notice) cause frequent care emergencies which have been particularly problematic for working carers.

Despite the expense involved, nearly all working carers surveyed had to have a private car in order to ensure that they could access the support services they needed and get to their workplace. However, 23% of families in England and Wales with a sick or disabled child have no access to a car or van^{xvi}.

Carers also have problems accessing leisure services and other social activities due to the cost and a lack of accessibility.

What do carers do?

Providing care can range from helping with the shopping on a regular basis to providing continuous care. The 2000 General Household Survey (GHS)^{xvii} found that:

- 51% of the carers looking after someone within their own home provided personal care such as bathing, washing, dressing and toileting.
- 57% provided physical help with getting in and out of bed, walking and getting up and down stairs.
- 26% were involved in providing personal care such as washing, 22% administering medicines and 71% give other practical help.^{xviii}

The General Household Survey also found that where the carer and the person cared for lived in the same household the amount of care provided increased. 63% of carers in the same household spent 20 or more hours a week caring and 31% spent at least 50 hours per week caring.

For whom do they care?

The Census question did not ask who the carer cared for, however the 2000 GHS revealed that more than half of carers (52%) were caring for their parents or parents in law, while 18% were caring for their spouse.

Nearly one in ten (8%) care for a child (including adult children), while a further fifth (21%) care for another relative and a fifth (21%) for a friend or neighbour.

Most carers look after elderly people. The 2000 GHS indicated that 70% of those cared for are 65 years or over. Sixty two percent of carers look after someone with a physical disability, 6% with a mental disability and 18% with both a physical and mental disability.



The importance of carers?

Most health and community care is provided by family, friends and relatives – the UK's six million carers. Social services and the NHS rely on carers' willingness and ability to provide care. This care is worth an estimated £87 billion per year – nearly as much as total spending on the NHS.^{xix}

In addition, research by Carers UK in 2002^{xx} found that carers contribute around £1 billion per year to supporting the community; through setting up and running self-help groups for carers, campaigning for and running carers' projects and centres, running Crossroads Schemes, setting up parents groups for children with disabilities, raising money for charities and many other essential activities.

Support for carers

Social services support

Carers have a right to an assessment of their needs by social services, regardless of whether the person they care for has had an assessment. In total, 414,000 carers were offered an assessment or a review in 2007-08. 51% of all carers who had an assessment or review were aged between 18 and 64, 18% aged 65-74 and 29% aged 75 or over.

The majority of carers (378,000) accepted the offer of an assessment. Of these, an estimated 337,000 (89%) received a service, 62% of all age groups were offered specific services, and 38% were offered information only.

In 2005-06 most carers (245,000) were assessed or reviewed jointly with the person they care for, but 89,000 were assessed or reviewed separately. 142,000 carers received a carer's service following assessment or review by council carer managers. This included some 7,700 carers who received a direct payment as at March 2007.

Services for carers include short breaks (also known as respite care), help around the home or anything else that helps the carer, such as a course or leisure activity. The number of breaks for carers, as reported by councils, increased by 15% from 2004-05 to an average of 20,520 per council in 2006-07. 40% of these breaks were for older people.

Financial support

There is a range of financial support for carers. The main benefit for carers is called Carer's Allowance and is the lowest benefit of its kind. The 2009-10 rate is £53.10 per week. It is the only benefit where the recipient has to certify to work a set number of hours per week. In this case you must be caring for at least 35 hours a week and you must not earn more than £95 from paid employment. The rate is the same regardless of how many hours you do or how many people you care for. In September 2008 a House of Commons Select Committee said the benefit was out of date and called for it to be radically reformed.

In November 2008, there were **496,140** people receiving Carer's Allowance in Great Britain. This means that just under 1% of the total UK population is receiving Carer's Allowance. There were a



further **419,240** people in Great Britain who were entitled to Carer's Allowance but not receiving any payment as they are receiving another benefit such as Incapacity Benefit or a State Pension.

Taking into account both those who are receiving Carer's Allowance and those with entitlement to it, **915,380** people in Great Britain have made a successful claim for Carer's Allowance.

As of August 2008, 50,381 people in Northern Ireland were entitled to Carer's Allowance, of whom 31,307 received the Allowance.

Carers may be entitled to other benefits, depending on their income and personal circumstances. More information can be found at www.carersuk.org/Information/Financialhelp.

Change over time

Figures for the total number of carers in the UK have fluctuated since 1985 between 6 and 7 million. The most recent figure, of 6 million carers, comes from the 2001 Census. Prior to the Census, UK estimates for carers have been based on the General Household Survey (GHS) covering England, Scotland and Wales and the Health and Social Well-being Survey in Northern Ireland.^{xxi}

However, one clear trend has emerged since the 1985 GHS, which is the continued increase in the number of carers providing in excess of 20 hours care per week. This figure has risen from 1.5 million in 1985 and 1990, to 1.7 million in 1995, to 1.9 million in 2000. This rise is confirmed by the 2001 Census, which also gives a figure of 1.9 million.

Figures on the number of carers providing 50 or more hours per week have also increased to 1.25 million in the 2001 Census. Previous GHS figures from 1985 to 2000 had fluctuated between 750,000 and 850,000.

Carers UK's research has suggested that the number of carers is likely to increase in the future. Carers UK's 2002 report *It could be you* demonstrates that demographic change, coupled with the direction of community care policy, will see a 60% rise in the number of carers needed by 2037 – an extra 3.4 million carers^{xxii}. Furthermore, the research showed that every year over 2.3 million adults become carers and over 2.3 million adults stopped being carers and that 3 in 5 people will be carers at some point in their lives.

Key Legislation

The following legislation has been achieved as a result of successful campaigning by **Carers UK**, **Carers Wales**, **Carers Scotland** and **Carers Northern Ireland** and numerous local and national carers' organisations.

Work and Families Act 2006

This act gave carers the right to request flexible working from their employer, which came in to force on 6th April 2007. It will affect around 2.65 million carers and means that they can ask their



employer to change their work pattern. It can only be refused if it will damage the business or have an impact on other employees.

Carers (Equal Opportunities) Act 2004 (England and Wales)

The Act came into force on 1st April 2005 in England and on 18th April in Wales. The principal aims of the Act are to:

- Ensure that work, life-long learning and leisure are considered when a carer is assessed.
- Give local authorities new powers to enlist the help of housing, health, education and other local authorities in providing support to carers.
- Places a duty on local authorities to inform carers of their right to an assessment.

The Carers and Direct Payments (Northern Ireland) Act 2002 and Community Care and Health (Scotland) Act 2002 provide similar provisions for Northern Ireland and Scotland.

Carers and Disabled Children Act 2000

The Carers and Disabled Children Act 2000 came into force in April 2001 in England and Wales. This Act provides:

- A right for a carer to request an assessment of their needs, even when the disabled person refuses an assessment. The carer has to be aged over 16 and has to be providing or intending to provide regular and substantial care for someone aged over 18.
- A right for parents of children with disabilities to request an assessment.
- The power for local authorities to provide carers with services which help them to care.
- The ability for local authorities to provide direct payments (ie cash instead of care) to parent carers, carers for their own services and young disabled people aged 16 or 17.
- The ability for local authorities to charge carers for their own services.
- Vouchers for breaks services.

Carers (Recognition and Services) Act 1995

The Carers (Recognition and Services) Act came into force April 1996. This Act:

- Gives carers who are providing 'regular and substantial care' the entitlement to request an assessment of their ability to care (a carer's assessment). Local authorities must take the carers ability to care into account when looking at what support to provide the person in need of care.

Who is Carers UK?

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, access to 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.

Carers UK Research

Carers UK has produced extensive research on all issues affecting carers. To download free PDF versions of our research reports, visit www.carersuk.org/Policyandpractice/Research. To receive a copy of our publications catalogue please contact our publication order line on 020 7566 7626 or visit Carers UK's website www.carersuk.org

Become an Affiliate Member of Carers UK

For as little as £50 per year organisations can ensure they are kept in touch with the latest developments and information on carers and caring. Call 020 7378 4931 to speak to our membership manager.

Training and consultancy service

Carers UK runs training days for professionals working with carers. The courses, run by leading lawyers, policy experts and practitioners, range from introductory or advanced community care law, to carers' benefits, advocacy, etc. Visit www.carersuk.org or call the Carers UK Training Unit on 020 7378 4942.

Carers UK's consultancy service provides organisations with the information they need to develop their work with carers. Our experienced consultants can review carers' services, develop strategies to improve provision for carers and help to improve the way that carers are consulted in planning strategies and services, reviewing employment practices and helping employers develop carer-friendly practices, ensuring that all work done is based on consultation with carers and other interested parties.

Carers UK helpline

Carers UK provides high quality advice and information to carers and the professionals who support carers. This is available through our websites, booklets, factsheets and our helpline – CarersLine. CarersLine is staffed by experts and has years of experience of dealing with the problems carers face. We provide information and advice on:



- benefits and tax credits
- carers employment rights
- carers' assessments
- the services available for carers
- how to complain effectively and challenge decisions.

Call 0808 808 7777 (Open Wednesday and Thursday 10am-12pm and 2pm-4pm. Answerphone at other times).

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Legal information

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London, SE1 4LX.

ⁱ Central Statistics Unit (2004) *Community Care Statistics 2002*. Scottish Executive, Edinburgh.

ⁱⁱ *Informal Carers Report. A report from the Health and Social Wellbeing Survey (1997)*. Department of Health, Social Services and Public Safety, Northern Ireland.

ⁱⁱⁱ *Real change not short change*. (2007) Carers UK, London.

^{iv} *Carers in crisis*. (2008). Carers UK, London.

^v *In Poor Health: the impact of caring on health*. (2004) Carers UK, London.

^{vi} Singleton N. *et al.* (2002) *Mental Health of Carers*. Office for National Statistics, The Stationery Office, London.

^{vii} Hirst M. (2004) *Health Inequalities and Informal Care*. Social Policy Research Unit, University of York.

^{viii} Hirst M. (2004) *Hearts and Minds: the Health Effects of Caring.*, Carers UK, London.

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^x Hirst M. (2004) *Hearts and Minds: the Health Effects of Caring.*, Carers UK, London.

^{xi} *Back Me Up: Supporting Carers When They Need It Most.* (2005), Carers UK, London.

^{xii} *We care. Do you?* (2005) Carers UK, London.

^{xiii} *Who cares wins: statistical analysis on working carers*. (2006) Carers UK, London.

^{xiv} *More than a job: working carers: evidence from the 2001 Census*. (2006). Carers UK, London.



- ^{xv} *Carers, services and employment report series.*(2007) Carers UK , London.
- ^{xvi} *Managing more than most: a statistical analysis of families with sick or disabled children.* (2006) Carers UK , London.
- ^{xvii} *Carers 2000* (2002) Office for National Statistics. London.
- ^{xviii} Office for National Statistics Social Services Division (1993) *General Household Survey 1990* HMSO, London.
- ^{xix} *Valuing carers - Calculating the value of unpaid care.* (2007) Carers UK, London.
- ^{xx} *Adding Value: Carers as drivers of change* (2002) Carers UK , London.
- ^{xxi} *Carers 2000* (2002) Office for National Statistics, The Stationery Office, London.
- ^{xxii} *It Could Be You – A report on the chances of becoming a carer* (2001) Carers UK , London.