

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

Facts About Carers

April 2004

What is a carer?

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

How many people are carers?

The latest figures on carers are from the 2001 Census¹. This indicated that there are 6 million carers throughout the UK, 10% of the total population, or approximately 12% of the adult population.

Until now, UK estimates for carers have been based on the General Household Survey (GHS)² covering England, Scotland and Wales and the Health and Social Well-being Survey in Northern Ireland³. This gives a total of over 7 million carers throughout the UK, 16% of all people aged over 16 - around one million more than the Census. However, because the Census is based on a survey of all households, rather than an estimated national figure, the UK Census figures are now the most commonly used.

There are a number of reasons why the figures could vary. The General Household Survey is a more detailed analysis, based on a sample of around 17,000 individuals from around 10,000 households, with national estimates made from these data. Because the survey involves an in-depth interview it is more likely to pick up lower end carers (i.e. people who care for a few hours per week) that may be missed by the Census. However, because it is an estimated national figure rather than a survey of all households, a margin of error could arise because of this.

Other studies indicate there are over one third of carers start or cease caring in any one year and each year there is a 6.6% chance of any one of us becoming a carer.⁴

The numbers of carers providing support for 20 hours or more every week has increased, from 1.5 million in 1990 to 1.7 million in 1995 to a figure of 1.9 million in both the 2000 General Household Survey (GHS) and the 2001 Census.

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CARERS UK

The Census also indicates that the number of heavy-end carers, those providing over 50 hours of care per week, has increased to 1.25 million. This is double the proportion of carers from the 2000 GHS.

Statistics about carers in Wales, Scotland and Northern Ireland

The 2001 Census indicates a higher proportion of adult carers in Wales than England, 16% compared to 12%. A similar difference was found in the 2000 GHS. This difference is explained in part by a higher rate of disability in Wales.

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.⁵

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.⁶

More information is available from Carers Wales, Carers Scotland and Carers Northern Ireland.

Who are the 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%). This gender split (58% to 42%) is identical to that identified in the 2000 GHS.

The peak age for caring is between 50 to 59. More than one in five of people aged 50-59 (1.5 million across the UK) are providing some unpaid care. One in four women in this age group are 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.

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 providing care for 50 hours or more per week.

However there are problems with the way that the figures are constructed. The statistics show a large number of young people providing between 1 and 19 hours of care a week to a disabled, frail or chronically ill person, approximately 85% of all young people providing care fall in this category. Unfortunately, this lack of detail masks some important issues. 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 UK found that 77% of carers who responded to the survey were worse off financially as a result of becoming carers, mostly attributable to the extra costs of disability within the family.⁷ Four out of ten carers said that charges for community care services caused major financial problems.

A third of carers in this survey qualified for Income Support, almost all respondents in the survey received Carer's Allowance (formerly known as Invalid Care Allowance) and nearly six out of ten carers lived in households where nobody was earning.

Health

The impact of caring can be detrimental to the health of carers. Carers UK's research has found that seven out of ten carers worried about their finances and six out of ten believed this had an effect on their health.⁸ A 2002 study 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 under 20 hours of care. 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.⁹

This research is backed up by the 2001 Census findings, which showed 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.

In addition nearly 260,000 people providing 50 or more hours of unpaid care per week state they are in 'not good health' themselves and this group are more than twice as likely to be in 'not good health' as those not caring (20 % against 9%). 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%).

The combined effects of poverty and ill health can lead to isolation and social exclusion for carers and leave carers ill equipped to return to work if caring ends.

Carers in the workplace

The 2001 Census found that over 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 i.e. 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.

Combining paid work and looking after a relative or friend causes stress and can lead to carers giving up work. In a survey carried out by Caring Costs in 1996, 49% of carers canvassed had given up work to care.¹⁰ In this survey, one half of carers in employment provided care for 100 hours a week as well as holding down a job. Nearly 73% of these said their earnings were affected by caring. Their average weekly loss was £121.73 and average annual loss was £5,625 (1996 wage levels).

What do carers do?

Providing care can range from helping with the shopping on a regular basis to providing continuous care. The 2000 GHS 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% administer medicines and 71% give other practical help.¹¹

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 one in three carers (38%) were caring for their parents, while 18% were caring for their spouse.

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 £57 billion per year – the equivalent of UK spending on the NHS.¹²

In addition, research by Carers UK in 2002¹³ 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 carers' centres, running Crossroads Schemes, setting up parents groups for children with disabilities, raising money for charities and many other essential activities.

How much help do carers get?

Over a third of all carers in the 2000 GHS reported that they were the only carer (33%) compared to 23% of carers in both the 1985 GHS and 1990 GHS and 35% in the 1995 GHS.

For carers who live in the same household as the people they care for:

- 56% stated that they were the only carer (42% in the 1985 GHS).
- 75% of the people receiving care from a carer living in the same household had no regular visits from professionals such as a doctor, district nurse or social worker.
- The proportion of such households receiving visits from doctors and health visitors has gone back up to 1985 levels – 12% received visits from a doctor in 2000 (13% in 1985 but only 8% in 1995). Five percent received a visit from a health visitor.
- A Carers UK study in 2003¹⁴ found that just 32% of respondents had had a carer's assessment. A Carers UK in 2000 indicated that the Carers' Special Grant at that time only went a short way to meeting local demand for short term break services.¹⁵ Since then, funding has increased.

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.¹⁶

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 number of carers providing 50 or more hours per week have also increased to 1.25 million in the 2001 Census. Previous General Household Survey 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 carers¹⁷. 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.

Community Care (Delayed Discharges etc.) Act 2003 (England)

Part II of the Community Care (Delayed Discharges etc.) Act dictates that certain community care and carers' services provided through intermediate care, must be provided free of charge to the disabled older person and carer for up to six weeks. These services include intermediate, aids and adaptations costing £1,000 or less. Part 1 of the Act gives a carer who requests an assessment, a right to be assessed and have any necessary services provided, before the patient leaves hospital. Part 1 of the Act also introduces a new fining system for local authorities, where patients' discharge from hospital are delayed by lack of services.

Carers and Direct Payments (Northern Ireland) Act 2002

The Act came into force in April 2003. The Act gives carers the right to a separate assessment of their needs. Many of the Act's provisions bring in legislation for carers in Northern Ireland in line with that of England and Wales.

The Act also places a duty on Health Boards to inform carers of their possible entitlement to an assessment.

Community Care and Health (Scotland) Act 2002

The Act came into force on 1 September 2002 and entitles all carers, including those under the age of 16 to request an assessment of their own right. Local authorities have to take account of the views of carers when undertaking an assessment of the person being cared for and they are under a duty to inform individuals of their possible entitlement to an assessment. The Act also has a number of significant differences to the England, Wales and Northern Ireland Acts and further information can be obtained from **Carers 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 (i.e. cash instead of care) to parent carers, carer 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. This section has yet to be brought into force, but is expected later in 2002.

Carers (Recognition and Services) Act 1995

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

- carers who are providing 'regular and substantial care' are entitled 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.

What do carers need?

Carers have raised the principles, which need to be kept in mind by policy makers, planners and commissioners of services. Carers need:

- Recognition and respect - of their role and for their knowledge
- Choice – about whether or not to care and a choice in support for carers
- A decent income – higher benefits and pensions
- Rights – to services and better rights for disabled people
- Consultation – about decisions which might affect them
- Information – about rights, benefits, services, medication, etc.
- Provision of practical help – services which are high quality, flexible and appropriate
- Minimal costs of caring – making services and equipment affordable or free
- Co-ordinated services – between health, social care, housing, education
- Well trained professionals – who understand the impact of caring and how to support carers

Who is Carers UK?

Carers UK is a registered charity run by carers, for carers. We:

- raise awareness at all levels of government and society of the needs of carers;
- seek solutions and change for carers;
- provide carers with information and advice. Our CarersLine answers over 20,000 carers enquiries a year;
- provide information via our website; www.carersonline.org.uk
- have a wide range of booklets on all aspects of caring;
- provide Policy and Parliamentary briefings for professionals on a wide range of issues relating to caring;
- provide training for professionals working with carers;
- lead Action for Carers and Employment (ACE National) an innovative partnership aiming to address the barriers faced by carers who wish to work;
- run offices in England, Scotland, Wales and Northern Ireland to tailor policy work, information and campaigns to meet the diverse needs of carers;
- support carers with a network of branches and groups throughout the UK;
- campaign for change - organise UK-wide campaigns, including our annual take-up campaign Carers Rights Day.

Carers UK Research

Young Carers and Education: (2003)

Written by Chris Dearden and Professor Saul Becker from Loughborough University, the report draws together existing research and evidence on young carers and education in the UK. The report shows that the growing body of literature provides clear evidence that significant caring responsibilities undertaken by a child can have a negative impact on their education. It also

examines literature on bullying and concludes that bullying is more likely to be a result of stigma towards disability within the family than the young person's caring responsibilities. The report is only available from:
www.carersonline.org.uk.

Missed Opportunities: The impact of new rights for carers (2003)

An England-wide study of the impact of legislation on carers' lives, based on a survey of carers' experiences obtaining support services to enable them to have choices about how they lead their lives, including family life, opportunities to work and maintaining good health. Specifically, it looks at the role played by carers' assessments in identifying and addressing carers' needs. The study also includes a survey of ten local authorities' responses to the policy changes. Full report priced £5.00 from Carers UK, summary available from
www.carersonline.org.uk.

Adding Value: Carers as drivers of change (2002)

Based on a UK-wide survey of carers, this report is the first to examine the role of carers as drivers of change. It looks at the extent to which carers become involved with local health and social care organisations and their contribution to supporting disabled people and carers through the voluntary sector. The report has important implications for anyone involving and consulting carers, working on regeneration, social exclusion or developing vibrant local communities. Summary available at www.carersonline.org.uk. Full report priced £5.00 from Carers UK.

Without Us? Calculating the value of carers' support (2002)

This report places a monetary value, of £57 billion, on the support that carers provide, updating previous work carried out in 1993. It also contains a comprehensive breakdown of the estimated number of carers and how much their support is worth in each local authority in England, Wales, Scotland, and Health and Social Services Boards in Northern Ireland. Priced £5.00

Paying the Price: Carers, poverty and social exclusion (2001)

Written by Marilyn Howard, a leading social policy expert, *Paying the Price* is one of the most comprehensive studies to date drawing together existing research and statistics to examine the poverty and social exclusion that affects carers. The report explores issues across the lifecycle – from caring at a young age to older carers over pension age – and the transitions into and out of caring. Published in conjunction with Child Poverty Action Group. Priced £9.95

... It Could Be You – a report on the chances of becoming a carer (2001)

As the population ages, Carers UK commissioned a report into the increased likelihood of becoming a carer, making a powerful argument for increased financial, health and social care support needed from Government and local authorities. Priced £5.00

Caring on the Breadline – the financial implications of caring (2000)

A survey exploring the financial circumstances of carers across the UK, focusing on whether and in what ways carers financial circumstances change as a result of caring and the impact that these changes have on the lives of carers. It also details what changes carers believe the Government could make to improve their financial circumstances. Priced: £10.00

You can take him home now – carers’ experiences of hospital discharge (June 2001).

A UK-wide study to examine whether carers’ experiences of hospital discharge has changed since 1998. It examines whether good practice is being followed in terms of informing, supporting and valuing carers at the point of hospital discharge. Available at: www.carersonline.org.uk Free

Each nation office produces its own research and can be obtained from the offices listed below.

Training for professionals

Carers UK also 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.carersonline.org.uk or call the Carers UK Training Unit on: 020 7566 7632.

Become an Associate of Carers UK for as little as £40 per year and ensure that you keep in touch with the latest developments and information on carers and caring. For further information ring: 020 7566 7602.

More information about carers’ issues

Contact Carers UK on 020 7490 8818. To receive a copy of our publications catalogue please contact our publication orders department on 020 7566 7626 or visit Carers UK’s website: www.carersonline.org.uk.

Carers 2000 is published by the Stationery Office but is only available on the web at present at: www.statistics.gov.uk/statbase/product.asp?vlink=5756.

2001 Census Statistics are available from:

For England and Wales visit: www.statistics.gov.uk/census2001/profiles

For Scotland: www.gro-scotland.gov.uk/grosweb/grosweb.nsf/pages/censushm

For Northern Ireland visit: www.nisra.gov.uk/census

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