



# **Our Health, Our Care, Our Say** *for Our Caring Future*

**Carers' priorities for a new National  
Strategy for Carers**

**February 2007**

# **Our Care, Our Health, Our Say for Our Caring Future: Carers' priorities for a New National Strategy for Cares**

## **Summary**

In January 2006 the White Paper Our Health, Our Care, Our Say promised to update and extend the 1999 National Strategy for Carers. To help inform this work Carers UK undertook a large scale survey of carers to see what their priorities were. This was to ensure that the new Strategy reflects carers' priorities and effectively identifies and tackles barriers to their full participation in society.

Nearly 3,000 carers responded to the survey. **One in five carers identified recognition by professionals as their highest priority.** Carers also cited services for disabled, elderly or chronically ill people, income levels for both working age and retired carers, and carers' health as very important.

Carers UK is calling on Government to ensure that the new Strategy addresses these issues and to set out its vision for supporting carers over the next decade and beyond. In terms of addressing carers' immediate priorities, the package of measures first unveiled in the White Paper, and launched in February 2007 as the 'New Deal for Carers', is welcomed by Carers UK. Emergency support during times of crisis, a national advice and information service and training for carers have all been identified by carers as immediate unmet needs.

## **What are carers' lives like?**

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Caring can happen at any time in your life, it is not predictable and is something that most people do not plan for. However, it is something that most people will end up doing at some time in their lives.

Currently there are six million people caring in the UK and around 2.2 million people either start or stop caring every year. Carers give so much to society yet as a consequence of caring they experience ill health, poverty and discrimination.

One in five carers has had to give up work to care because they find it so hard to juggle caring with work. They cannot stop caring because alternative care is not available, so work is the first to go. More than three-quarters of carers have become financially worse off since becoming a carer and the longer someone is a carer, the more likely they are to be on a poor income - those caring long term are more likely to be

in receipt of Income Support. Carers providing over 50 hours of care per week (there are 1.25 million of these in the UK) are twice as likely to suffer ill-health as those not providing care.

Carers do not always have a choice about caring, but most people, given the choice, would continue to care. It is something they do out of a sense of duty or love. The vast majority of people do not see themselves as carers but as mothers, fathers, brothers, sisters, partners, wives, husbands, sons, daughters or close friends.

Carers' support has been valued at a staggering £57 billion per year, which is what it would cost to replace them if they stopped caring. By 2037, the number of carers would have to increase by half again to 9 million to keep pace with the rising levels of frailty and disability – at a time when the paid workforce is shrinking.

Since 1999, there have been changes which have helped carers such as increased benefit levels, money for local authorities to provide carers' breaks and measures to support working carers. However, carers still feel that they face significant barriers in:

- remaining in and returning to work
- being recognised and valued for their role by society and professionals alike
- maintaining their health and well-being
- enjoying their right to have a family life
- keeping up social and family ties because they cannot get the breaks they need
- having a life beyond caring, training or taking part in leisure activities.

As an organisation of carers and the voice of carers, Carers UK believes that there remains a strong agenda for change which must be tackled.

### **What are carers' priorities?**

In December 2006 and January 2007, Carers UK carried out a survey of carers. It covered a wide range of carers from around the UK, including older and younger carers, men and women, working carers and those who are not in paid work, and carers looking after a range of different people. However, the vast majority of respondents were providing more than 50 hours of care each week.

The number of responses received (2950) provided Carers UK with strong evidence on carers' priorities for change. Carers were asked what they believed should be the priority for change from a list of options based on key issues that are raised by carers to Carers UK. They were asked to

rank their top three priorities. Carers UK believes these should be addressed in the National Strategy for Carers.

Carers' number one priority for change is **better recognition of the role of carers from professionals**, which was cited by 20% of respondents as their top priority. **Income from benefits for the under 65s** was cited by 16% as their top priority, and **better services for the person for whom they care** was cited by 15%.

Once second and third preferences were taken into account, recognition from professionals remained the number one priority. In total, 39% of respondents put recognition as their first, second or third choice. The second most popular options were services for the disabled person and carers' health (both 35%), followed by income in retirement at 32%, proving that retirement income is a priority for both the under 65s and the over 65s.

Just under half (49%) of respondents were under the age of 65. For them, the top issue was the income that they received from benefits (cited by 22% as their top priority), followed closely by recognition from care professionals (21%) and services for the disabled person (17%). Younger carers were more likely to rank breaks from caring and employment higher than those over 65.

The 51% of respondents who were over 65 ranked recognition from professionals as their top priority (23%). Income from retirement was second highest rated with 17% and services for disabled people at 16%. Older carers were more likely to prioritise and carers' health than younger carers were.

**Table 1: Carers' top priority for change by percentage of responses (n = 2950) and actual number of responses.**

<b>Carers' priorities</b>	<b>Ranked first most frequently (% of 2950)</b>	<b>Number of responses</b>
Recognition from professionals	20	581
Income from benefits for the under 65s	16	468
Better services for disabled/older/chronically ill people	15	443
Income in retirement	13	389
Carers' health	11	315
Breaks	9	278
Long term care	8	232
Employment issues	4	126
Housing	4	110
Carers' services	4	132
Opportunities for leisure and training	3	78
Status	2	60

*Note: These do not add up to 100 as some respondents marked some responses equal first and did not specify a second or third ranking.*

**Table 2: Carers top three priorities for change by percentages (n = 2950) and actual number of responses**

<b>Carers' priorities</b>	<b>Ranked first second or third most frequently (% of 2950)</b>	<b>Number of responses</b>
Recognition from professionals	39	1142
Better services for disabled/older/chronically ill people	35	1041
Carers' health	35	1030
Income in retirement	32	959
Breaks	29	848
Income from benefits for under 65s	29	846
Long term care	21	605
Carers services	19	559
Employment	11	338
Leisure and training opportunities	10	293
Housing	9	263
Status	2	298

## **Implications for the National Strategy for Carers**

This research highlights areas that Carers UK believes the Government should concentrate on in its review of the National Strategy for Carers. It highlights the cross-governmental nature of support for carers and the need to target different types of support at working age and retired carers.

## **What was the original National Strategy for Carers?**

Having carried out research in 1996 on carers' needs in relation to the care they provide, Carers UK began a campaign for a National Strategy for Carers which would pull together the different strands that affected carers' lives. In 1997, the process began and it was published in 1999 by the Prime Minister.

The first strategy was ground-breaking in that it:

- was the first cross-cutting strategy for carers
- was championed by the Prime Minister
- announced the first spending specifically on carers – the Carers Grant – which started at £20 million in the first year and is now worth £185 million per year
- paved the way for new legislation (Carers and Disabled Children Act 2000) so that carers could receive services in their own right
- took an in-depth look at carers and work for the first time, and also looked at carers' pensions
- included issues not normally discussed such as transport and housing.

Although the first strategy overlooked carers' benefits, Carers UK continued campaigning and launched its Fair Deal for Carers campaign in 2000. The Department for Work and Pensions was then able to provide the "missing part" of the strategy – the first major changes to carers' benefits for 15 years – in a package to benefit around 300,000 carers costing in the region of £500 million over three years.

## **What did the Strategy achieve locally?**

The Strategy included recommendations and standards of what Government expected local services to deliver e.g. it expected GPs to look at carers' needs. It also included good practice examples and recommended that local authorities develop their own strategies. This all led to the development of better joint working. Social services found it easier to engage other partners and new initiatives were developed.

## **Why do we need a review of the Strategy?**

For all its ground-breaking nature, the Strategy did not look beyond 3 to 4 years of its life. Since then, however, Government has introduced a number of measures which go beyond the Strategy, such as the Work

and Families Act which will give working carers the right to request flexible working from their employer. Carers UK has recommended to Government since summer of 2004 that they review the Strategy to take stock of where policy has been successful and review what still needs to be done.

The revised and extended Strategy needs to take account of the changing dynamics of caring and the changing structure of society. As carers' priorities and evidence from their daily lives show, there are major issues that need to be tackled such as:

- how can we change attitudes and understanding about carers among the general public and professionals?
- how can the current and future workforce juggle work and care?
- how should care be delivered?
- how do we make up the care deficit to ensure that families and friends get the support they need?
- how can we improve outcomes for carers in terms of their own health, well being and life chances?
- how do we tackle the discrimination that carers face in employment and the provision of goods and services?
- how can we integrate areas which are normally overlooked, such as housing and transport?
- how do we take into account the needs of minority groups and those most excluded?

### **What should the new strategy look like?**

The research from Carers UK which is outlined above shows the broad and challenging range of issues that carers wish to see addressed in the Strategy. Whether the strategy meets these challenges will depend on the way that it is designed and delivered. The issues that matter to carers do not fit neatly in to the responsibilities of one Government department so the strategy will require a truly cross-governmental approach which looks at the interactions between different areas of policy.

In order to have the greatest chance of meeting carers' expectations for a thorough and far-reaching piece of work, it is essential that the Strategy:

- is championed at the highest level, i.e. by the Prime Minister
- is informed by consultation with carers
- includes immediate changes, medium term commitments and long term vision – it should be a Strategy for the next 10 years and beyond
- considers changes that may be needed to primary and secondary legislation as well as guidance and good practice.
- sets out standards and values of what is expected of professionals

- highlights good practice and successes to act as catalysts for change

### **What will Carers UK be doing?**

Carers UK will play an active role in helping to shape the New Deal for Carers by providing evidence to Government on carers' priorities and providing opportunities for carers to input directly in to the Strategy.

### **What progress is Government making in the short term?**

As well as committing to updating and extending the National Strategy for Carers, the Government has announced a package of measures which will address some of carers' top priorities.

The package has been labelled the 'New Deal for Carers' and is worth £33 million in total. In addition to the Strategy it consists of three elements. They are:

- **£25 million will be allocated to local authorities in England to provide emergency support** consisting of short term, home-based support for carers in crisis or emergency situations
- **£3 million to be spent on a national advice and information service** to be set up and possibly run by a voluntary sector organisation to provide "reliable, detailed information" to help carers make decisions about their personal support, opportunities for them and the needs of the person they're caring for
- **£5 million for an Expert Carers Programme in England** – this will be aimed at providing training for carers to better self manage their own health and the health of those they are caring for.

### **How will the New Deal support carers?**

#### **Emergency support**

Emergency support during times of crisis will help to improve carers' short and long term health and well-being - a key priority for carers. Good emergency support and planning would make carers feel valued by professionals and it would provide better services for disabled people. Evidence from Carers UK's Back Me Up report<sup>1</sup> showed that emergency support and planning was sadly lacking with devastating consequences for carers. Carers UK therefore warmly welcomes the Government's announcement of funding for emergency support for carers.

#### **Advice and information service**

A national advice and information service for carers would address some of the issues faced by carers in terms of income both for those under 65 and in retirement. Around 40-60% of carers' benefits go unclaimed and the majority of people are unaware of their entitlements. The evidence

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<sup>1</sup> <http://www.carersuk.org/Newsandcampaigns/BackMeUp>



suggests that knowing about your entitlements keeps carers in work longer, and, for those out of work or retired, improves their incomes.

### **Expert carer programme**

By taking part in an expert carer programme, carers would gain increased recognition from professionals because they would receive formal accreditation from courses – valuing what they do day in, day out, to support their relative or friend in the community. It would also help to improve carers' health as evidence has shown that early training on lifting, handling and moving helps reduce the risk of injury and long-term illness or disability. Increased feelings of confidence and a reduction of stress can also help to reduce depression. A Carers UK survey found that nearly half of those providing very substantial care i.e. over 50 hours per week, had been treated for a stress-related disorder since they started caring.

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This briefing is supported by funding from the European Social Fund's Equal Community Initiative Programme and is also part of our Equal Partners project, seeking to involve and engage carers.



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