

Report to: **Adult Social Care Scrutiny Committee**

Date: **2 July 2009**

By: **Director of Adult Social Care**

Title of report: **Services for adult carers in East Sussex**

Purpose of report: **To update the Committee on plans for implementation of the East Sussex joint carers commissioning strategy 2010-2015**

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## **RECOMMENDATIONS**

**The Adult Social Care Scrutiny Committee are recommended to:**

- 1. receive the background information on carers services**
  - 2. support the aims and objectives of the strategy**
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### **1. Financial Appraisal**

1.1 East Sussex County Council is spending £2.3 million in 2009/10 on services for adult carers. Since the publication of the first national strategy for carers in 1999 a specific pot of funds has been allocated to Councils to spend on carers' services, but this amount was no longer ring-fenced after 2004. However, East Sussex has continued to earmark an equivalent sum each year for carers' services.

1.2 The new strategy for carer's services is a joint commissioning strategy with the local Primary Care Trusts. As part of the new national strategy for carers published in 2008 additional funds for respite services for carers were directed towards the NHS. Services within the new strategy will be delivered within allocated ASC and PCT budgets.

1.3 Services implemented as a result of the success of the Carers Demonstrator site bid to the Department of Health will be delivered within the agreed budget.

### **2. Background and Supporting Information**

2.1 A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. The economic value of the contribution of carers in the UK is estimated to be £87 billion per year (see Appendix 1).

2.2 East Sussex recognises the need to support carers. Its Sustainable Community Strategy "Pride of Place" 2008-11 incorporates key objectives to support carers across health and social care services. This includes a commitment to reach specific targets to increase the numbers of carers receiving a service, advice or information following an assessment of their needs. In 2008/9 we have increased the number of carers receiving an assessment as a proportion of people receiving community-based services to just over 22% (compared to 19% nationally).

2.3 A profile of the budget spent on carers services in 2009/10 is shown in Appendix 2. Case studies on two projects funded through the carers' budget currently are given in Appendix 2.

2.4 In response to the new national carers strategy (Executive Summary Appendix 3) we have published a draft proposed joint local strategy for carers (Appendix 2). Local priorities have been identified based on the results of a questionnaire which was sent out to 3,200 local carers (response rate 29%).

2.5 It is clear from the consultation that the services currently provided are valued by local carers, and we will seek to strengthen and develop the methods of support already being provided. However, there is a lack of equity and accessibility, particularly in terms of respite provision, that we need to address. Funding constraints mean that we will need to commission innovative services that reach out to the most carers possible. We will maximize opportunities to use the knowledge and added value that trusted voluntary sector organisations can contribute, including support for volunteers, but will also welcome other organisations who can play a part in delivering services.

2.6 We believe that in East Sussex we should focus available funds on three key areas: respite, support to stay mentally and physically well, respect for and involvement of carers in service planning. We intend to develop and take forward the implementation of personalised services in line with the Putting People First agenda, and maintain and develop an even lighter touch system of awarding individual grants to meet agreed outcomes for carers.

2.7 We have been successful in bidding to the Department of Health to become a “demonstrator site” for providing flexible respite services to people with dementia and their carers across the county through the Older People’s Community Mental Health Teams. This is based on a current project funded by ESCC (see Appendix 2). The value of this service is £610,000 over two years.

2.8 We are awaiting the result of an additional bid submitted jointly with the PCT to become a demonstrator site for working with GP surgeries and in local hospitals to raise awareness of and provide support to carers in those settings. The value of this service, delivered through Care for the Carers (the local carers’ centre affiliated to the Princess Royal Trust for Carers) is £532,000 over two years.

### **3. Conclusion and Reasons for Recommendation**

3.1 The Committee is requested to encourage local participation in the consultation for the strategy in order to ensure that as many local people as possible have an input into our plans. The consultation period for the draft strategy ends in early September, following which we will be taking it to the Lead Member and to ESSP for approval.

3.2 Current contracts for carers services are due to end in March 2010, following which new services will be tendered/commissioned based on the objectives of the new strategy.

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Director of Adult Social Care

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#### **BACKGROUND DOCUMENTS:**

**Appendix 1:** Valuing carers – calculating the value of unpaid care (Carers UK, 2007)

**Appendix 2:** Draft proposal for East Sussex joint commissioning strategy for carers’ services 2010-2015 (May 2009) including case studies: (a) The Glyndebourne project and (b) individual respite provided by the OPCMHT, South Wealden

**Appendix 3:** Carers at the Heart of 21st Century Families and Communities (Executive Summary, 2008)



## Facts about carers

January 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
<b>England</b>	4,877,060	10	998,732	20
<b>Northern Ireland</b>	185,086	11	46,912	25
<b>Scotland</b>	481,579	10	115,674	24
<b>Wales</b>	340,745	11	89,604	26
<b>UK Total</b>	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.<sup>1</sup>



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.<sup>ii</sup>

## 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 UK<sup>iii</sup> 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<sup>iv</sup> 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*<sup>v</sup>, 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.<sup>vi</sup>

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<sup>vii</sup> 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<sup>viii</sup> 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.<sup>ix</sup> 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.<sup>x</sup> 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.<sup>xi</sup>

Further details on carers' health are available in our policy briefing on Carers Health, available on our website: [www.carersuk.org](http://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.<sup>xii</sup>

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<sup>xiii</sup>.

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<sup>xiv</sup>.

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<sup>xv</sup>.



## 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<sup>xvi</sup>.

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)<sup>xvii</sup> 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.<sup>xviii</sup>

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.<sup>xix</sup>

In addition, research by Carers UK in 2002<sup>xx</sup> 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, 383,000 carers were offered an assessment or a review in 2005-06. 193,000 of these were aged 18-64 and 190,000 were aged over 65. The majority of carers (334,000) accepted the offer of an assessment. Most (245,000) were assessed or reviewed jointly with the person they care for, but 89,000 were assessed or reviewed separately.

In 2005-06, 142,000 carers received a carer's service following assessment or review by council carer managers. This includes 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 2008-09 rate is £50.55 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 February 2008, there were 508,476 people receiving Carer's Allowance in the UK. This means that just under 1% of the total UK population is receiving Carer's Allowance. There were a further **412,551** people in the UK 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, **921,027** people in the UK have made a successful claim for Carer's 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](http://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.<sup>xxi</sup>

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<sup>xxii</sup>. 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 6<sup>th</sup> 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 1<sup>st</sup> April 2005 in England and on 18<sup>th</sup> 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](http://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](http://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](http://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.

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

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

<sup>iii</sup> *Real change not short change.* (2007) Carers UK, London.

<sup>iv</sup> *Carers in crisis.* (2008). Carers UK, London.

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

<sup>vi</sup> Singleton N. *et al.* (2002) *Mental Health of Carers*. Office for National Statistics, The Stationery Office, London.

<sup>vii</sup> Hirst M. (2004) *Health Inequalities and Informal Care*. Social Policy Research Unit, University of York.

<sup>viii</sup> Hirst M. (2004) *Hearts and Minds: the Health Effects of Caring.*, Carers UK, London.

<sup>ix</sup> Hirst M. (2004) *Hearts and Minds: the Health Effects of Caring.*, Carers UK, London.

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

<sup>xi</sup> *Back Me Up: Supporting Carers When They Need It Most.* (2005), Carers UK, London.

<sup>xii</sup> *We care. Do you?* (2005) Carers UK, London.

<sup>xiii</sup> *Who cares wins: statistical analysis on working carers.* (2006) Carers UK, London.

<sup>xiv</sup> *More than a job: working carers: evidence from the 2001 Census.* (2006). Carers UK, London.

<sup>xv</sup> *Carers, services and employment report series.* (2007) Carers UK, London.

<sup>xvi</sup> *Managing more than most: a statistical analysis of families with sick or disabled children.* (2006) Carers UK, London.

<sup>xvii</sup> *Carers 2000* (2002) Office for National Statistics. London.

<sup>xviii</sup> Office for National Statistics Social Services Division (1993) *General Household Survey 1990* HMSO, London.

<sup>xix</sup> *Valuing carers - Calculating the value of unpaid care.* (2007) Carers UK, London.

<sup>xx</sup> *Adding Value: Carers as drivers of change* (2002) Carers UK, London.

<sup>xxi</sup> *Carers 2000* (2002) Office for National Statistics, The Stationery Office, London.

<sup>xxii</sup> *It Could Be You – A report on the chances of becoming a carer* (2001) Carers UK, London.

**DRAFT  
PROPOSAL FOR  
EAST SUSSEX JOINT COMMISSIONING STRATEGY FOR CARERS' SERVICES  
2010 – 2015**

**A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.**

[Carers at the Heart of 21<sup>st</sup> Century Families and Communities, 2008]

This proposed strategy has been agreed between East Sussex County Council Adults Social Care Department and the two NHS Primary Care Trusts in East Sussex for the support of adult carers in East Sussex over the next five years.

Separate, inter-linked strategies are being developed for the support of young carers and of parent carers of children with disabilities by East Sussex County Council Children's Services Department and the two NHS Primary Care Trusts.

The strategy to support adult carers has been discussed widely and many groups and individuals have made suggestions which we have tried to include in this final version of the plan. It sets out what sort of services we intend to provide or to commission from third sector organisations within the constraints of limited funding, according to the priorities identified from national and local research, including Carers UK and the Princess Royal Trust for Carers.

It builds on the services that we already provide and on what we have learned since we implemented our previous joint commissioning strategy for carers in 2007.

### **Why support carers?**

There are 6 million carers in the UK and every day over 6,000 people take on a caring role. The ageing population within which we live means that our chances of becoming a carer has increased, so it is therefore essential to have a system of responsible long term care planning.

23% of the population of East Sussex is over 65 (compared with 17% in the South East, and 16% in England overall). Trends predict that this percentage will increase to 25% by 2013, and that by 2015 over 10,000 people will have dementia (source: ESIF)

The number of carers in East Sussex is estimated to be 50,648 (approximately 10% of the population), the majority of whom are in the age range 50-64. This figure is based on the number of people who identified themselves as providing unpaid care to family or friends in the Census 2001, but it could be a lot more because of the fact that many people do not identify themselves as carers and may not have responded positively to the census question.

Research has shown that carers are more likely than the rest of the population to suffer depression and develop other health problems (Carers UK, 2004). This was reflected in the results of research carried out locally in 2006 by the University of Brighton.

Carers should be recognised and valued for the enormous contribution they make and for the hard job that they do every day. We should be looking after carers and supporting them in accessing a

range of services and support. We should ensure that we look after the health and wellbeing of carers and enable them to take regular short breaks.

In 1998 the Kings Fund produced a “Carers Compass”, setting out the things that carers need. These are:

- a good quality of life for the person they care for and control of their own life.
- full information
- a voice
- financial security
- training and support to care
- emotional support
- time off
- a life of their own – quality services for the carer and the person cared for
- recognition
- their own health and well-being taken into account

This research has informed the development of carers’ services throughout the country ever since.

## **The vision**

The aim of this strategy is:

- To respond to what carers across all care groups have identified as the key issues now and in the future
- To comply with existing carers’ legislation giving carers the right to an assessment of their own needs, and in addition with the Carers (Equal Opportunities) Act 2004 and the Work and Families Act (2006) that should enable carers to access education, skills development and lifelong learning opportunities
- To respond to the document published by the Government in December 2007 entitled “Putting people first: a shared vision and commitment to the transformation of adult social care” which follows the White Paper published in 2006 “Our Health, Our Care, Our Say”, setting out its commitment to provide carers with better prevention services and earlier intervention, support to maintain mental health and emotional wellbeing and to give carers choice and diversity. Three levels of intervention are recognised. All need to be sensitive to the needs of all carers (see “Putting People First without putting carers second” published by the Princess Royal Trust for Carers, 2009). These are for:
  - universal services – broadly community-based, such as leisure, lifelong learning, primary health care and preventative services
  - targeted services aimed at the most vulnerable in our society – typically for carers include training to care, stress management, advocacy and health promotion
  - personalised services to aid people whose needs have been assessed and are at risk – these services are usually provided by the local authority and include home care support and access to regular short breaks.

Putting People First maps out the transformation of adult social care services by 2011 by means of partnership working with the NHS and the third sector to bring about personalised, flexible services, responsive to individual need.

- To implement the key themes of the updated cross-departmental strategy for carers: **“Carers at the heart of 21<sup>st</sup> century families and communities”** which was published by the Government in June 2008, setting out a vision for the future care and support of carers for the next 10 years.

The main aims nationally for adult carers are set out as follows:

- Carers will be respected as expert care partners
- Carers will have access to the integrated and personalised services they need to support them in their caring role
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity.

This document was produced after extensive national consultation, and builds on the key needs identified in the Kings Fund Carers’ Compass.

It also updates the definition of a carer to include those caring for a relative, partner or friend with mental health or substance misuse problems.

## **What has been achieved so far**

The first national strategy for carers was produced by the Government in 1999, and a specific pot of funds was made available annually by the Department of Health to Local Authorities to spend on carers’ services.

Since 2003 this funding is no longer “ring-fenced” by the Government, but East Sussex County Council have continued to spend a significant proportion of its Adults Social Care budget on carers’ services year on year.

East Sussex recognises the need to support carers. Its Sustainable Community Strategy “Pride of Place” 2008-11 incorporates key objectives to support carers across health and social care services. This includes a commitment to reach specific targets to increase the numbers of carers receiving a service, advice or information following an assessment of their needs.

### **Current services for carers in East Sussex**

East Sussex commissioned the University of Brighton to undertake some research in 2005-6 to look at the needs of local carers and whether existing services were adequate to support them. In 2007 East Sussex produced a Joint Commissioning Strategy for Carers Services 2007-2010, which was agreed after wide consultation with carers and the organisations that support them, as well as the University of Brighton research.

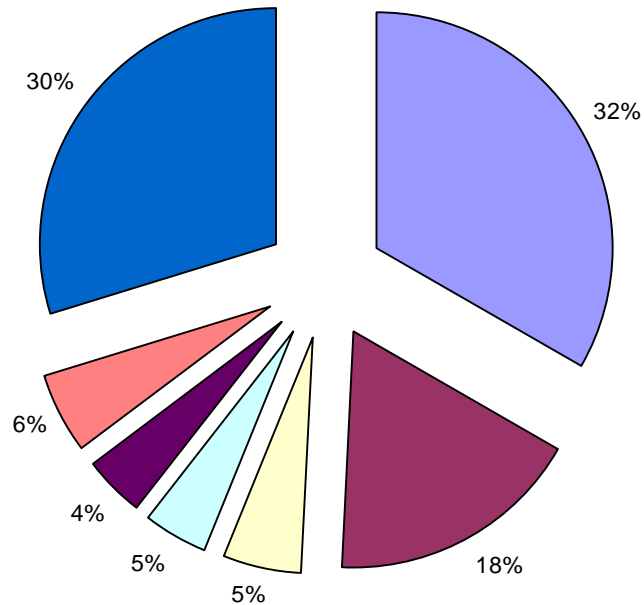
In 2009/10 East Sussex County Council and the local Primary Care Trusts are spending £2.5 million on funding services for adult carers. This is in addition to the resources involved in the statutory duty of undertaking the assessment of individual carers’ needs.

This funding is targeted as follows:-

- **Home-based care and respite services:** these are mainly “sitting” services provided by a trained careworker or volunteer through Crossroads, Association of Carers and the British Red Cross, but sometimes can be where a specialist worker takes the cared for person out while the carer has a break.  
"thankyou for giving me those Friday afternoons. L (cared for person) was always very pleased to see you and I was always comfortable to leave you together in the knowledge that L was in your calm, protective hands" (see Appendix D for case study)
- An emergency respite service was piloted in 2008/9 to provide care in the home for 48 hours in the event of a carer being unable to look after the person they care for because of emergency hospital admission, dental care, or if their employment would be under threat. This scheme has been evaluated and changes proposed in order to implement the scheme fully in 2009/10.
- **Emotional support, advice and information** provision through Care for the Carers, a generic organisation supporting carers, but also through specialist organisations such as Rethink, Motor Neurone Disease Association, Action for Change, Sussex Deaf Association
- **Day services for the cared for person:** specialist provision for people with learning disabilities provided by Mencap and Circles, and for people with dementia provided by the Alzheimers Society and Crossroads
- **Training activities for carers:** a small proportion of funding goes to organisations to provide training related to specific conditions, e.g. dementia, stroke and vision awareness training, as well as for stress-reduction and leisure activities, such as MBCT or photography. In addition, training activities are provided regularly by Care for the Carers, Rethink etc. Back care advice and access to equipment is provided by Care for the Carers.
- **Outings and support groups:** these include days out for carers and those they care for, e.g. trips to the Bluebell railway, circle dancing or coffee mornings – see Appendix B for case study
- **Awareness-raising:** it is recognised that many carers don't identify themselves as such and therefore don't have access to services. Third sector organisations such as Care for the Carers and the Alzheimers Society are commissioned to play a key role in reaching out to isolated and seldom heard carers in rural and/or deprived areas.
- **Direct individual grants to carers:** nearly £3/4 million has been spent in 2008/9 on direct grants to support carers. As part of an assessment or review of their needs, carers may apply for a grant for funds to spend on a break or service that will help them in their caring role.  
"I am thrilled to bits with my new camera.....I did not think I needed help..... but it has changed my whole outlook.....made a great change in my life. You lit up an otherwise dark corner"  
  
"My time at the gym is spent on myself and I can completely forget about the longterm situation at home for an hour a week. Thank you so much!"



## Profile of Budget for Carers Services 2009/2010



■ Home based care and respite	■ Emotional support, advice and info
■ Day services for cared for	■ Training activities
■ Outings and support groups	■ Awareness raising
■ Individual Grants	

### Monitoring of services

- The county-wide Carers Strategy Group is the accountable body for all carers' services in East Sussex. This is a partnership of statutory and voluntary sector organisations who support carers, and carers themselves. Carers make up at least one-third of the membership of the Group and are from different areas of the county and care for people with a range of care needs.
- The Carers Development and Planning Group is facilitated by Care for the Carers and chaired by carers. It is an independent voice for carers and their representatives in the planning, development and monitoring of services, and elects representatives on to the Carers Strategy Group.
- The Carers commissioning sub-group is composed entirely of carers and commissioners of services. It meets quarterly to receive monitoring reports on commissioned organizations, and makes decisions on commissioning new services when funds are available. This includes the allocation of "development funds" to innovative projects in order to pilot possible development of new services.

## Consultation

A range of methods of ongoing consultation have been used to seek out views of carers, service users and the general public since the last local strategy for carers was produced in 2007. These include:

1. Locality Focus Groups held by Care for the Carers during 2008: 5 focus groups across the county were held, attended by 54 carers. Results showed that carers value groups and courses but respite is an issue – Carers Respite Training Budget set up. *“We are only human beings, we can only run for so long”*. Carers also highlighted transport issues, and asked for more information generally, particularly via GP surgeries
2. Survey of ESCC staff in November 2007 received 190 replies. Key themes from the replies were:-
  - A need for information and support about carers’ services
  - Benefits advice
  - More flexible working, particularly working from home
  - More support for the person cared for to fit in with their working role.*“It affects my energy levels and mental well-being (stress, anxiety, emotional upset) - it's not always easy to hide this and it does affect my performance and productivity at times”*
3. Summer 2008 workshops and “road shows” held by East Sussex Downs & Weald PCT revealed that the participants felt preventing hospital admission is the number one priority for consideration when commissioning services, along with the promotion of safe, high quality care and the prevention of disease.
4. Furthering Long Term Independence Workshop in October 2008 attended by service users and carers. The health and support needs of carers were seen as a priority, in particular the identification of carers via GPs in order to initiate preventative measures.
5. “Closer to Home” stakeholder events were held jointly by the Primary Care Trust and Adult Social Care throughout East Sussex in October and November 2007, revealed the provision of information and access to services, as well as service user involvement and better joint working to improve service delivery as key priorities. Healthcare priorities included:-
  - better access for rural population and for people with disabilities
  - out of hours services
  - end of life care
  - *specific health needs of carers.*

In order to ensure that this strategy responds both to Government legislation and the needs of local carers, a questionnaire was sent out to 3,200 local carers in January 2009 via Care for the Carers and Rethink asking them for their views on the priorities highlighted by the Government in “Carers at the heart of 21<sup>st</sup> Century Families and Communities”. A 29% response rate was achieved, including many additional individual comments, indicating a high level of interest and strong views about support needs from carers themselves.

Clear support for the key priorities was evident from the responses to this and previous consultations, focusing on:

- The need for carers **to be listened to**, for professionals to be trained to recognise carers, specifically health professionals/GPs:  
*“Not to be patronised by someone on a first visit who has never met the person I care for. In this instance I am the most experienced on care”*
- Varied **respite**, individually tailored to need. A primary concern for carers is to know that the person they care for is well looked after, and people mentioned flexible and out of hours services, based at home:  
*I would like to have a break but I would NOT put my husband into a home*
- **Emotional support** from voluntary organisations and from other carers; this is very much valued, but transport to enable carers to get to places is often an issue:  
*To have contact and know support is available + in the back ground - this helps keep stress levels down*
- Easy access to **information** – it is evident that this needs to be in a variety of media in order to be available for all, and that leaflets need to be simplified.  
*Most important would be information and easy access to speak to someone if there were any questions within the information that people would like to ask.*

However, analysis of the responses revealed that the demographics of the respondents did not necessarily reflect the county wide figures, and further efforts will now be made to consult with under-represented groups:-

	<b>% of respondents</b>	<b>% across county</b>
Aged over 65	50%	23%
From a BME community	1.3%	5.2%

See Appendix C for a full breakdown of responses.

## **The way forward**

East Sussex County Council and the local Primary Care Trusts are committed to providing funds to support carers' services as part of a partnership approach to addressing the health and social care needs of the local population.

It is clear from the consultation that the services currently provided are valued by local carers, and we will seek to strengthen and develop the methods of support already being provided.

However, there is a lack of equity and accessibility, particularly in terms of respite provision, that we need to address. Funding constraints mean that we will need to commission innovative services that reach out to the most carers possible. We will maximize opportunities to use the knowledge and added value that trusted voluntary sector organisations can contribute, including support for volunteers, but will also welcome other organisations who can play a part in delivering services.

We believe that in East Sussex we should focus available funds on three key areas that have been identified by the Government's strategy and as a result of the latest consultations with carers:

1. **Respite/breaks**
2. **Support to stay mentally/physically well**
3. **Respect and involvement**

All quotations are taken from the responses to the January 2009 survey.

### **Respite options**

- A menu of flexible, individually tailored home-based respite care services supplied by local, trusted providers from the third sector; to include out-of-hours and specialist support:

*I would like to be able to have occasional Saturdays off but am not often able to find carers to come in to sit with my husband.*

- In order to ensure equity of access for all carers, respite can be accessed through the Council's care management process by accredited providers, with some financial contribution from those who are able, following an assessment of need:

*Better and reliable respite services at a reasonable cost in the home of the cared for person would be a good idea.*

- The continued use of the system of individual Carer Support Grants for those whose needs cannot be met elsewhere and to ensure maximum choice and control for carers, including working carers:

In order to continue to develop the Putting People First ethos and the move towards individual budgets controlled by service users, we intend to look at ways of reducing the level of bureaucracy entailed at the moment in the administration of these grants, moving further towards monitoring and recording outcomes for the carers who receive them.

*The carers grant has allowed me to have a short holiday for the last 2 years. It helps to re-charge your batteries and also gives the person you care for a break from you. It has made a great difference to my life*

- Emergency respite care to be available to all carers, managed through the voluntary sector: the process to be simplified to ensure equitable access for all – consideration to be given to a system of making a minimal annual charge for the service: *To be able to access someone when wanted eg for an unexpected necessary visit eg Doctor etc*
- Consideration also needs to be given to the use of residential respite and how to ensure that this is accessible and up to the high standards that carers should be entitled to expect.

## Support to stay mentally/physically well

- Emotional support, information and advocacy services to be provided by the voluntary sector – both generic carer organisations and those supporting carers of people with specific needs, e.g. substance misusers, stroke survivors:

*Someone to share the load, someone to talk to who understands your problems*

- Access to training to help in the caring role and to reduce stress and isolation, peer support groups, outings and activities:

*Clubs or groups where carers can meet other carers in the same situations, timed to fit in with the taking and collecting of the handicap person! social meetings for carers - possibly with organised transport.*

- Information provision needs to be enhanced and more accessible in a variety of media, through the voluntary sector and through trained social care staff who can signpost carers to appropriate sources of support, including the new National Carers Telephone Helpline set up by the Government.

*To have 24/7 365 telephone line providing support and advice this would encourage mental health*

- Support from GPs and other health professionals:

*The most important person to have on your side is an understanding proactive GP./ Bring back regular visits by District Nurses*

## Respect and involvement

- Staff training to be provided to ensure that carers are recognised and valued as equal partners in care by health and social care professionals:

*Expert Medical/Schools should listen to us and our experience/ involvement in decision making instead of the "we know best" attitude. Much better communication on both sides*

- A Carers Charter to be implemented in health and social care settings, and service specifications for all organisations commissioned to work with all care groups to include an obligation to work better with carers:

*To share information about the cared person. To be given accurate information about the mental health condition of cared person. To be given recognition of the care.*

- Carers should be involved in hospital admission and discharge processes and Care Passports universally recognised:

*"Provide care agency with "care passport" like for hospital admission. They only see a small snapshot of the person. It doesn't help if you say they were not good in afternoon to be told they were good in the morning!"*

- Carers to be fully involved in assessment and review processes, both their own and of the person they care for:

*To share information about the cared person. To be given accurate information about the mental health condition of cared person. To be given recognition of the care.*

- Regular Carers Forums to be held throughout the county to enable carers to speak directly to senior managers, commissioners and service providers, and outcomes acted upon and fed back to the County wide Carers Strategy Group:

*More meetings and better rapport with professionals*

## **Governance and equity**

We recognise that carers should be involved at all levels of the commissioning cycle, not just in the assessment of their own needs. We intend to build on the current level of involvement of carers in planning and monitoring services by providing adequate support and training to carers in a Carers Development Group that has clear lines of accountability and elects members to the Carers Strategy Group. This group will be fully and actively involved in commissioning decisions that affect carers and in the local LINK network – see Appendix A for full proposals.

To ensure that the needs of carers are recognised and prioritised by all services, we will ensure that the Equalities Impact Assessments that are carried out as part of the implementation of all new services include carers as a category.

We recognise that carers do not necessarily identify themselves as such, and we need to ensure that awareness-raising work continues with the general public as well as in community settings to ensure equity of access, and we will continue to invest in providing clear, accessible information to publicise services.

We will ensure that as employers we recognise the needs of staff who are carers, and will work proactively with other employing organisations in the county to encourage the implementation of carers' charters for staff, flexible working options and awareness-raising.

## **Conclusion**

We recognise that support for carers needs to be integral to service delivery in all areas, and will work towards this as a long term goal, including commissioning joint services for service users and carers together that value the needs and individual choices of both.

We will ensure that health and social care professionals work more pro-actively with carers in community and acute hospital settings, promoting the new guide for GPs published by the Princess Royal Trust for Carers and the Royal College of General Practitioners 2009, and providing adequate training for staff.

We will implement the aims of Putting People First, and aim to provide choice and control for carers, responding flexibly to individual need.

We are committed to providing adequate services for carers that respond to both government legislation and local need, and we recognise that carers have essential requirements in order to them to carry out their role of caring. The vision will be challenging from a corporate perspective

but will also create new opportunities for carers that have previously been denied. We recognise that financial constraints will mean that choices have to be made, and funds targeted where they will have most impact according to identified need.

We will consult with the public about this strategy and the results will be incorporated into the final document. We will particularly target under-represented groups (referencing Beyond We Care Too, the Afiya Trust 2008).

We also recognise that former carers have their own needs and may need support to move on, but also have valuable insights and can have a part to play in advising on the governance of this strategy.

The overarching County Carers Strategy Group will be the accountable body for all carers' services, and each workstream will report back on a regular basis to this group.

Annual action plans for each workstream will then be written, sub-groups set up with carer as well as voluntary and statutory sector representatives, to report back to the Carers Strategy Group. This strategy will be reviewed annually by the Carers Strategy Group.

May 2009

**Appendix A:** *Proposed new structure for monitoring of East Sussex joint commissioning strategy for carers 2010-2015 (Pages 12-16)*

**Appendix B:** *Case Study: Glyndebourne outing (Pages 17-20)*

**Appendix C:** *Full responses from January 2009 survey (Pages 21-38)*

**Appendix D:** *Case Study: Older People's Community Health Care Team (Pages 39-40)*

## APPENDIX A

### **PROPOSED NEW STRUCTURE FOR MONITORING OF EAST SUSSEX JOINT COMMISSIONING STRATEGY FOR CARERS 2010-2015**

The updating of the strategy 2010-15 gives an opportunity for us to review the structure of the groups that are responsible for its implementation and monitoring.

#### **Current structure**

- **Carers Strategy Group**

The Carers Strategy Group (CSG) is a partnership of organisations and individuals who all have an equal voice at the table. It is intended to provide a forum for all the agencies and interest groups concerned with carers in East Sussex to meet together and take a broad overview of carer related issues in all aspects of planning and service delivery, including advising on the allocation of available resources.

**Membership:**

Adult Social Care

Children's Services

PCTs

Community and Acute NHS Trusts

Borough and District Councils

Key Countywide Voluntary Organisations representing carers

at least 8 current or recent carers, nominated by the Carers Development Group and representing, as far as possible, the range of client groups and the geographical spread of the county (East, West, Rural). Nominees will serve a year but may be re-nominated by the CDG

Representatives from other groups and agencies may be co-opted as necessary, by agreement with the group.

Carer members are entitled to Reward & Recognition and expenses payments through ESCC Adults Social Care.

**Meetings:**

Will be held at least every two months and will be chaired by a senior officer from ESCC Adult Social Care or the PCTs.

**Sub Groups:**

The CSG may set up one or more sub-groups to undertake more detailed work on parts of its agenda. The groups will remain accountable to the CSG.

- **Carers Development and Planning Group**

The Group aims to provide a local voice for carers and professionals who work directly with carers, or who represent carers.



**Membership:**

Voluntary organisations that support carers  
East Sussex County Council – Adult Services & Children's Services  
East Sussex Downs and Weald Primary Care Trust  
Hastings and Rother Primary Care Trust  
East Sussex Hospitals NHS Trust  
Sussex Partnership NHS Trust  
Local Authorities – Local Strategic Partnerships

And aiming for at least an equal number of carers or ex-carers, who should as far as possible reflect carers across the county, the majority having had recent experience of caring.

**Meetings:**

Held every six weeks and chaired by carer or ex-carer members, who are elected annually by the group. The group is facilitated and serviced by Care for the Carers, and carers are therefore not able to claim Reward & Recognition payments, although expenses for attendance are paid.

There is no clear pathway of accountability and feedback to other groups, although regular update reports are given to and from the CSG.

- **Carers commissioning sub-group**

The function of this group is to support the implementation of the action plans to take the strategy forward by agreeing funding for small new projects that fit with its aims, and by monitoring existing services commissioned through the Carers Grant.

This group has no terms of reference. There is no clear pathway of accountability and feedback to other groups, although regular update reports are given to the CSG and CDPG.

**Membership:**

The group consists of carers and ex-carers recruited informally through the CDPG, as well as commissioners and finance officers from Adults Social Care who are co-opted as necessary for monitoring and discussions. Its focus is entirely on adult carers. Carer members are entitled to Reward & Recognition and expenses payments through ESCC Adults Social Care.

**Meetings:**

Held approximately quarterly, and chaired by the Strategic Commissioning Manager for Carers (ASC).

- In addition, there is a **Carers Services Network**, which is a group of representatives from organisations commissioned through Carers Grant to share information and best practice, which meets quarterly and is chaired by the Strategic Commissioning Manager for Carers/Carers Project Officer.
- The **Carers Liaison Group** is a group of professionals from statutory and voluntary organisations who work directly with carers, and meets quarterly to share information and best practice. It is chaired by the Strategic Commissioning Manager for Carers/Carers Project Officer.

# PROPOSAL FOR FUTURE STRUCTURE

## 1. Carers Strategy Group

It is proposed that the terms of reference of the CSG remain as they are.

This enables the group to represent carers' interests across the county as widely as possible without becoming cumbersome.

Having carers nominated through the Development Group means that they have access to the following support:-

- Relevant training (see later)
- Pre-briefing and an opportunity to discuss upcoming agenda items (which will be sent out in advance and will be discussed at the relevant CDG meeting)
- Support during CSG meetings
- An opportunity to debrief and feedback after the CSG meeting
- Carers members will be entitled to Reward & Recognition and expenses payments through ESCC Adults Social Care

The CSG will have an additional remit to receive reports and feedback from the quarterly Carers Forums held throughout the county (see later).

## 2. Carers Forums

It is proposed that Carers Forums are held quarterly at different venues across the county. These events will be open to all carers and will be facilitated and managed by Care for the Carers. They are an opportunity for carers to come together with managers and practitioners from statutory services who are involved in delivering services to them and to those they care for. The aims of the Forums will be:

1. To give carers a voice and to enable them to engage regularly with managers of services
2. Actively to promote the role and needs of carers, and their value to society as a whole and within health and social care settings
3. To consult regularly with carers on all relevant Health and Social Care provision and to provide regular feedback to the Carers Strategy Group on developments and issues.
4. To enable carers to be nominated to the Carers Development Group and/or other relevant local service planning and development groups and partnerships who will undertake to represent the views and needs of carers and report back to the CSG.
5. To monitoring the effectiveness of services as they affect carers: including the range, quality and quantity of locally identified needs and services.
6. To discuss, comment on, inform and contribute to local strategic planning and national legislation that will affect carers. Each forum will provide an opportunity for local decision makers to consult with carers on new initiatives, and for external speakers to be invited to present information as appropriate.

7. To look at developing new ways of working with carers in partnership with all agencies.
8. To contribute to the County Carers Strategy by highlighting and promoting local issues and concerns.
9. To address specific issues of wide carer interest or concern.

These aims in essence mirror the aims of the current Carers Development Group, but will allow the expansion of ad hoc, informal and interest-based membership that will enrich the voice of current carer experience throughout the county, and give decision makers a regular opportunity to engage with a broad range of carers.

### 3. Carers Development Group

It is proposed that this group is composed entirely of carers who wish to participate. Members will be supported to join the group through Care for the Carers or nominated to the Group by other voluntary sector organisations, and through Carers Forums, but the group will be facilitated by staff from Adults Social Care.

This is in order to maintain and strengthen the independence of the group, and to enable them to be reimbursed properly for their participation, whilst continuing to be supported and trained on an ongoing basis.

The criteria for carer members will remain as currently, and members will be supported to join the group by the Partnerships Manager of Care for the Carers, who will facilitate the training opportunities as part of their work funded by Adults Social Care.

Training will be offered on a regular basis, but in addition carers may wish to become representatives of the East Sussex Local Involvement Network in Health and Social Care (LINK), a body of people from the local community who have certain statutory powers (see [www.thecountylink.net](http://www.thecountylink.net)). This cross-representation will enable those who wish to incorporate the skills they learn in this capacity to enhance their contribution to the CDG, and vice versa. In this respect Care for the Carers will work closely with East Sussex LINK to provide support and training for carer members. This training will include:-

- Induction training for new members, to include specific training about Local Authority and NHS procedures, commissioning processes and terminology
- Training about carers' issues
- Assertiveness and confidence building training
- Training around understanding issues of representation.

The training will be provided either locally by Care for the Carers and/or the LINK or nationally through Carers UK or the Princess Royal Trust for Carers.

Carer members will be entitled to Reward & Recognition and expenses payments through ESCC Adults Social Care (and expenses only when acting as a member of the LINK, through its own mechanisms).

It is therefore proposed that the **Commissioning Sub-Group** is subsumed entirely within the Development Group, in order to ensure fair and equitable nomination processes and access to effective support.

This group will have an annual election to nominate at least 8 current or recent carers representing, as far as possible, the range of client groups and the geographical spread of the county (East, West, Rural) to sit on the Carers Strategy Group. Nominees will serve a year but may be re-nominated by the CDG.

It is proposed that the CDG will meet six-weekly in advance of the CSG, and occasionally on an ad hoc basis as and when requested.

The Strategic Commissioning Manager – Carers (Adults Social Care) will attend all meetings of the CDG, and other commissioners and finance officers will be co-opted on to the group in order to provide specific commissioning or financial advice at the request of the group members. Representatives from voluntary sector organisations will be invited to join the group on an ad hoc basis in order to provide updates on latest developments or discuss particular issues.

#### **4. Action Plan sub groups**

As at present.

#### **5. Carers Services Network Group**

It is proposed that the Carers Services Liaison Group is amalgamated into this group. This will give all professionals working with and supporting carers and opportunity to share best practice and information about new initiatives and developments. There will also be a clearer communication pathway to the Development and Strategy Groups.

In addition, there will be ad hoc interest- and area-based groups set up from time to time, e.g. for professionals working with people with learning disabilities, or organisations using volunteers to support carers, or for carers' champions within Adults Social Care and multi-disciplinary teams. Individual and more specific practice-based issues can be discussed individually outside the meeting.

The meeting will continue to meet bi-monthly and be chaired by the Strategic Commissioning Manager – Carers or Carers Project Officer (Adults Social Care).

## **APPENDIX B:**

### **THE GLYNDEBOURNE PROJECT**

*Kathy Fordham (Action in Rural Sussex) writes about the project held at Glyndebourne Opera House for people with dementia and their carers in Nov/Dec 2008*

*“Never was the stage of Glyndebourne Opera House more enthusiastically and passionately occupied by a group of singers, than on one cold damp Thursday, in late December 2008. They stepped boldly up to face the brilliantly glowing cavern which is the Glyndebourne auditorium and delivered a heartfelt rendition of the Portrait Song from the Magic Flute, which filled the vast space with its beautiful melody. This was followed by another musical gem, which as before, was accompanied by practised and expressive gestures. Sadly, there was no audience to appreciate the magic of the moment, but for once that didn’t seem to matter.”*

*(Martin Barnes - Trusts and Development Manager, Glyndebourne Opera House)*

*“We are provided with other help and opportunities to get together but so often, the events are in dusty and rather down-at-heel village halls. Being at Glyndebourne makes us feel respected and valued again. It’s such a lovely place and we get to share in its qualities.”*

*“It awoke something that was dormant in my husband, gave him a whole month of pleasure.”*

*“Something happened on Thursday mornings that was so unexpected and valuable that I am still thinking about it.”*

*“Quite remarkable - used to have real trouble getting Michael up, but getting up for Glyndebourne was easy!”*

*“It’s like a return to normal life. It feels like the kind of times we used to have.”*

*“The best thing was the lovely musicians and the venue”*  
*(Workshop participants)*

#### **The participants**

This description and these comments relate to a series of four workshops, held at the world famous Glyndebourne Opera House, involving musical experiences and performance linked to the music of the Magic Flute. The performers on the Glyndebourne stage were ten people with dementia plus their relatives, who care for them. They all live in the rural area around Lewes in East Sussex and had been identified by the Lewes Villages Dementia Outreach Service. Many of them have felt very isolated and have not been offered the range of services or facilities which they would experience in an urban area. Because they live in small communities, they sometimes feel stigmatised and ‘exposed’. There are few local services and often no public transport. Therefore, they have had little opportunity to socialise. Their needs are not prioritised by funders, who focus on developing services for people living in urban, ‘deprived’ areas.

#### **The Project**

The Glyndebourne project was developed through a partnership between Glyndebourne Festival Opera and the Lewes Villages Dementia Outreach Service, which is run jointly by the Alzheimer’s Society and Action in rural Sussex. Workers Kathy Fordham and Vicky Hill wanted both carers and their relatives with dementia to be offered high quality services and opportunities in non-

institutional and attractive settings, within the rural locality. Evidence suggests that group activities involving music can be particularly beneficial for people with dementia (Sachs 2008). Vicky was inspired by a visit to 'Turtle Song' in London, a singing project for people with dementia and their carers, run by the English Touring Opera and students from the Royal College of Music. Vicky and Kathy wanted to provide a similar opportunity locally and approached the world famous Glyndebourne Opera House. Katie Tearle, the Head of Education at Glyndebourne, eagerly embraced the idea, as the approach fitted well with their strategy of local engagement and having had experience of working on projects for people with particular needs, felt that they would be able to draw on artists with the right experience to deliver the programme and that their venue would be suited for the work. Kathy and Vicky agreed to identify match funding (Glyndebourne Education, as a regularly funded organisation of Arts Council England, were able to allocate some funding) and to advertise the project to local people with dementia and their carers. Cynthia Heymanson, a member of Glyndebourne and a freelance trainer in dementia care, volunteered to observe the sessions and individuals' responses, to contribute to the evaluation of their effectiveness.

The aims of the project were:

- To provide a high quality, enjoyable social activity which improves the sense of self-worth of carers and cared for
- To enable carers to meet each other and offer mutual support and sharing of information
- To provide enjoyment and stimulation in a 'safe', non-stigmatising setting
- To reduce social isolation and stress
- To improve the confidence of both carer and cared for that they can still participate in social activities and give them the confidence to access statutory services, such as respite, day care etc.

### **The Workshops**

The venue was the new Green Room at the Opera House, a comfortable room with sofas, props from various operas and a beautiful full length picture window looking out over the formal gardens and the South Downs. Four workshop sessions were offered, each lasting 1½ hours, every Thursday morning for 4 weeks. These were led by Sam Glazer and Julian West, two world class musicians who also have experience of working with people with dementia. Support was provided by Glyndebourne Education Department staff and by Kathy and Vicky, to ensure that participants experienced a warm, welcoming environment.

Each session began with refreshments and time to socialise, with plenty of props and photos on coffee tables to provide something to look at and a conversation point. Participants were then invited to join a circle with the musicians, who started by playing a piece of music from the Magic Flute. Each workshop offered various opportunities to listen and to play musical instruments, to sing, to reminisce and to create visual props and ended with another short performance from the musicians. The highlight of the final workshop was the opportunity to sing on the stage of the Opera House, as described earlier.

### **Evaluation**

The effectiveness of the project in meeting its aims was evaluated via:

- Systematic, coded observation by Cynthia Heymanson of the level of engagement and enjoyment of both carers and people with dementia at each session
- Recording of positive or other comments of the participants, both after each session and by carers completing a brief evaluation form after the final session
- Observations by the workers during the sessions

- Observation of changes in the behaviour, responses, and level of social interaction of the participants.

The evaluation was extremely positive and the project's aims were met. The coded observation demonstrated that both carers and people with dementia moved from an initial state of some anxiety and partial engagement to one of being mostly or fully engaged, with visible expressions of enjoyment and appreciation. Body postures became more relaxed and people with dementia became less restless.

The comments of the participants, including the examples quoted earlier, were also very positive and particular value was placed on the high quality of the musicians and the venue.

All of the workers involved found the project very rewarding and sometimes, deeply moving and enjoyed both the music and the interaction.

Both participants and workers felt afterwards that 2 hour sessions would have been preferable.

Participants made friends and Vicky, Outreach Worker, reported afterwards that attendance at support groups, coffee mornings etc. has increased and the atmosphere is much more sociable. The project has acted as a stepping stone for those reluctant/embarrassed to be involved in dementia related services previously and some have been encouraged to look into Day Care opportunities. Some of the people with dementia now continue to recognise Vicky and, some 2 months on, nearly all of them remember the Portrait Song. The people with dementia also come to social events with more enthusiasm than before - some thing safe and familiar about the Glyndebourne experience has been retained.

### **Future plans**

The participants were very keen to have additional opportunities to meet each other and to try other musical activities and the Lewes Villages Dementia Service is working to provide these. Glyndebourne are very keen to be involved with a further series in November 2009 and are interested in recruiting volunteers to support a choir for people with dementia and their carers, which would be led by a specialist musician

### **Lessons Learned**

- People with dementia are able to sustain concentration and interest for a two hour session
- Musical perception, sensibility, emotion and musical memory can survive long after other forms of memory have disappeared
- The opportunity to access really high quality activities at a top class venue made a huge difference to confidence and feelings of self worth, especially for the carers and gave them to impetus to seek other services
- If you have an exceptional facility in your locality, don't be afraid to ask!

**Kathy Fordham - Development Officer, Lewes Villages Project, Action in rural Sussex**  
**Vicky Hill - Outreach Worker, Lewes Villages Dementia Outreach Service, Alzheimer's Society**

### **Reference:**

Oliver Sachs, Professor of Neurology and Psychiatry, Columbia University - *Musicophilia*, 2008

NB: The Lewes Villages Dementia Carers Outreach Service started in 2007 as a partnership between the Alzheimer's Society and the Village Care Service at Action in rural Sussex (a local charity whose role is to provide practical help and support to villages in Sussex, assist in identifying needs and issues and champion the needs of rural communities with policy and decision makers).

Primary Care Practices in rural Lewes District had identified a number of people with dementia for whom no services were available, and a lack of support for family members who were caring for them. The outreach service therefore, was developed to identify carers of people with dementia in the rural areas; to provide and develop specialist information, support and advice to carers of people with dementia, including home visits, support to claim benefits and grants, information and signposting to services available, training for carers; to develop access to respite, social activities and support services; to provide opportunities for carers to meet and offer support to each other.

The service is staffed for 7 hours per week by an Action in rural Sussex Community Development Worker and the Alzheimer's Society provides an Outreach Worker for 22 hours per week.

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## **APPENDIX C:**

### **IMPROVING SUPPORT FOR CARERS \_ STAGE 1 SURVEY RESULTS**

**COMPILED APRIL 2009**

This is the raw data from the Improving Support for Carers survey conducted with members of Care for the Carers and ReThink in East Sussex in January and February 2009. The outcomes from the survey have been compiled using the data that follows.

#### **Notes about this data:**

Where figures do not add up to the total number of respondents, it is because some respondents left answers blank.

Written responses to free text questions about what would most improve services were clustered into themes for the purposes of analysis. The themes from this process are included here. The most common themes are more darkly shaded.

Often, people mentioned more than one issue in their written response. Where a respondent raised two issues, for example, they were counted once under each issue.

As you will see, there are often a relatively high proportion of responses under 'Misc' (miscellaneous). This reflects the great variety of individual concerns and needs identified by the carers surveyed. Responses were labelled 'Misc' when they raised personal issues related to very specific circumstances, or raised wider issues that were not raised by any other respondent.

The percentages for these questions do not count 'blanks': people who did not make any suggestions for improvements.

**About the respondents:**

<b>Response rate</b>		<b>29%</b>
	Sent out	3200
	Received	920
		29.00%

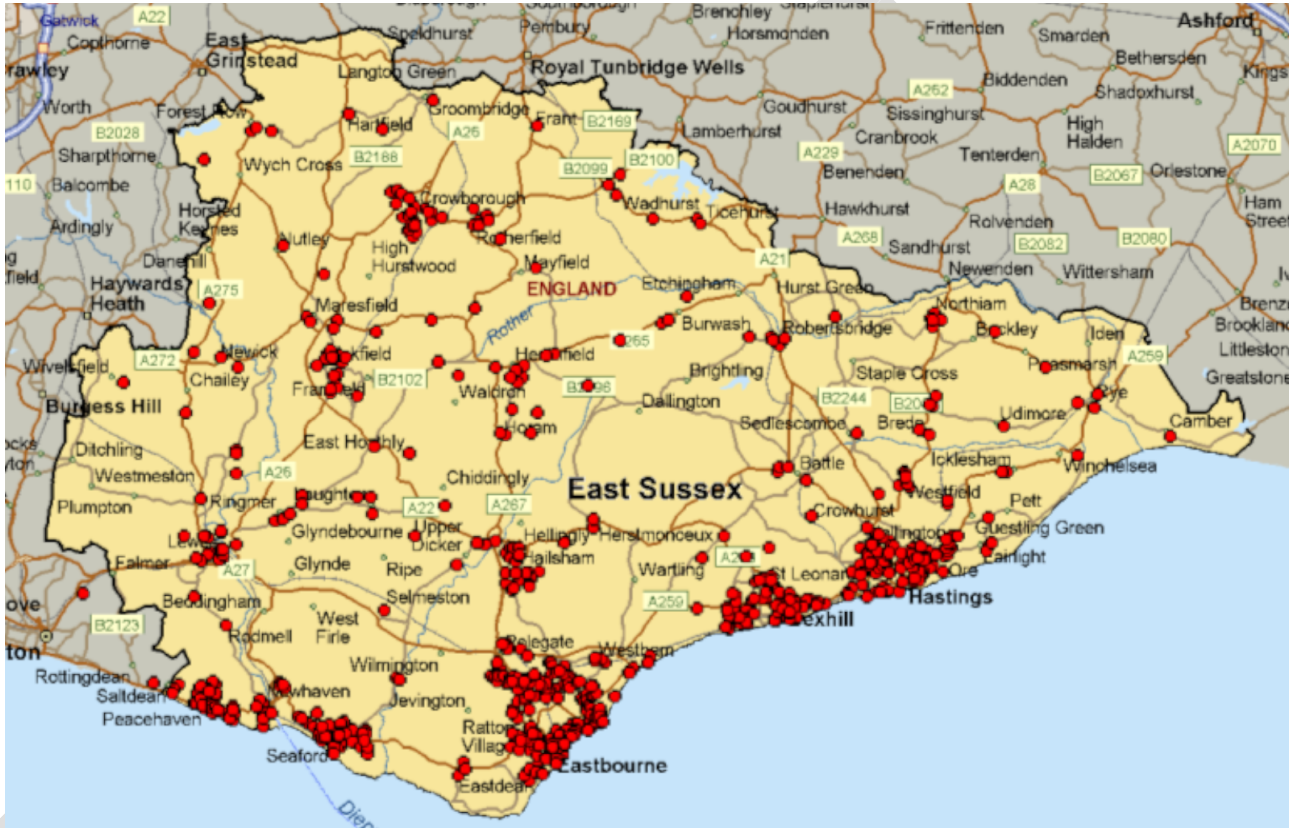
<b>Are you....?</b>	<i>Male</i>	233	25.95%
	<i>Female</i>	665	74.05%

<b>Which of these age groups do you belong to</b>			
	<i>18 to 24</i>	13	1.43%
	<i>25 to 34</i>	14	1.55%
	<i>35 to 44</i>	63	6.95%
	<i>45 to 54</i>	149	16.45%
	<i>55 to 59</i>	75	8.28%
	<i>60 to 64</i>	133	14.68%
	<i>65 to 74</i>	192	21.19%
	<i>75+</i>	267	29.47%

<b>Which of these best describes your ethnicity</b>		
<i>British</i>	864	96.75%
<i>Irish</i>	4	0.45%
<i>Gypsy/Roma</i>	1	0.11%
<i>Irish Traveller of Irish heritage</i>	0	0.00%
<i>Any other White background</i>	12	1.34%
<i>White and Black Caribbean</i>	0	0.00%
<i>White and Black African</i>	0	0.00%
<i>White and Asian</i>	2	0.22%
<i>Any other Mixed background</i>	2	0.22%
<i>Caribbean</i>	1	0.11%
<i>African</i>	0	0.00%
<i>Any other Black background</i>	0	0.00%
<i>Indian</i>	3	0.34%
<i>Pakistani</i>	0	0.00%
<i>Bangladeshi</i>	0	0.00%
<i>Any other Asian background</i>	0	0.00%
<i>Chinese</i>	2	0.22%
<i>Other ethnic group</i>	2	0.22%

<b>Do you consider yourself to be disabled as set out in the Disability Discrimination Act?</b>		
<i>I consider myself disabled</i>	183	21.43%
<i>I do not consider myself disabled</i>	671	78.57%

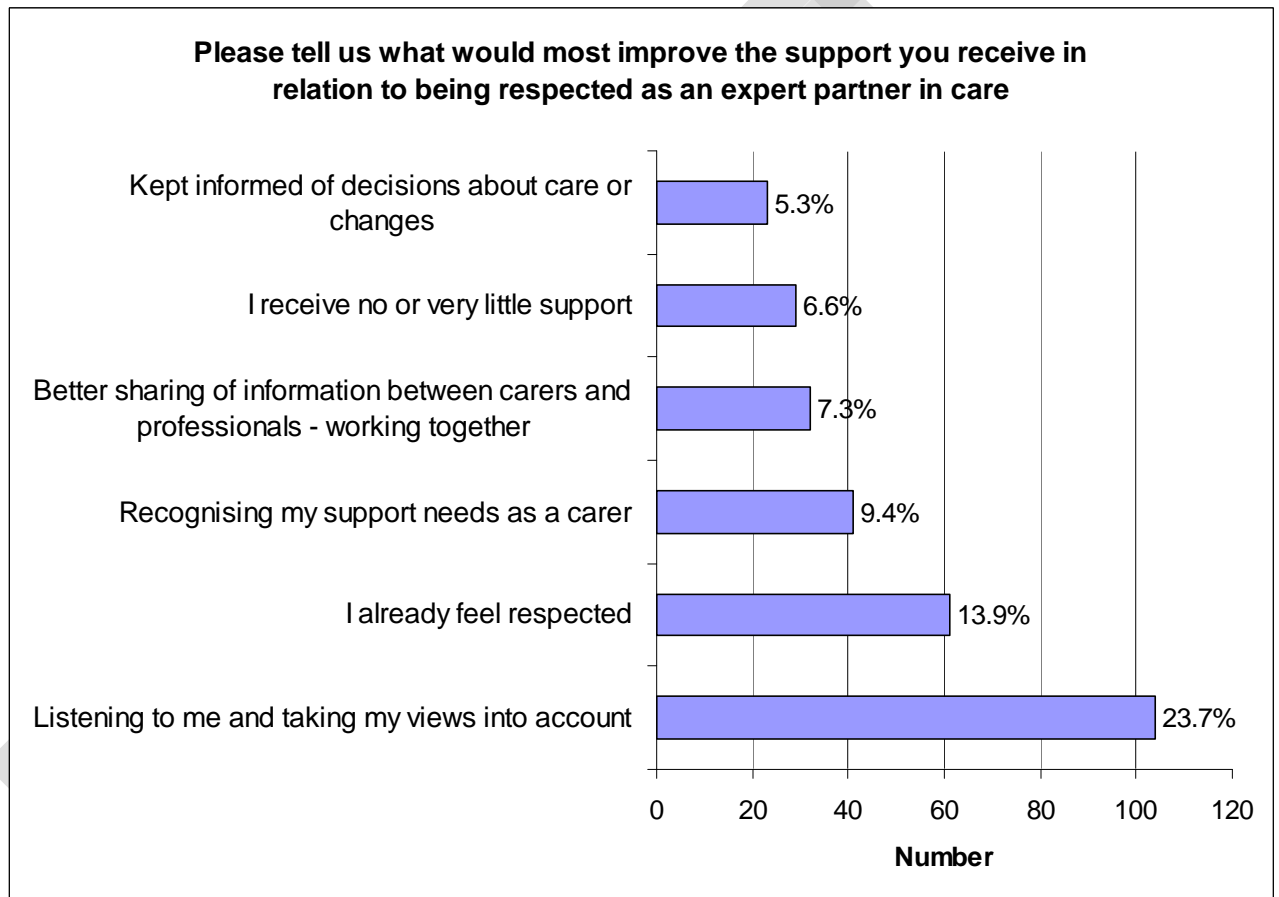
**Postcode breakdown – red dots indicate respondents:**



**Q1a**

**Carers should be respected by paid staff as expert partners in care**

<b>Q1.a.</b>						
<b>Carers should be respected by paid staff as expert partners in care</b>	<i>very important</i>	<i>Important</i>	<i>neither important nor not important</i>	<i>not important</i>	<i>not at all important</i>	<i>na</i>
	631	230	25	6	3	25
895 responses = 100%	70.5%	25.7%	2.8%	0.7%	0.3%	

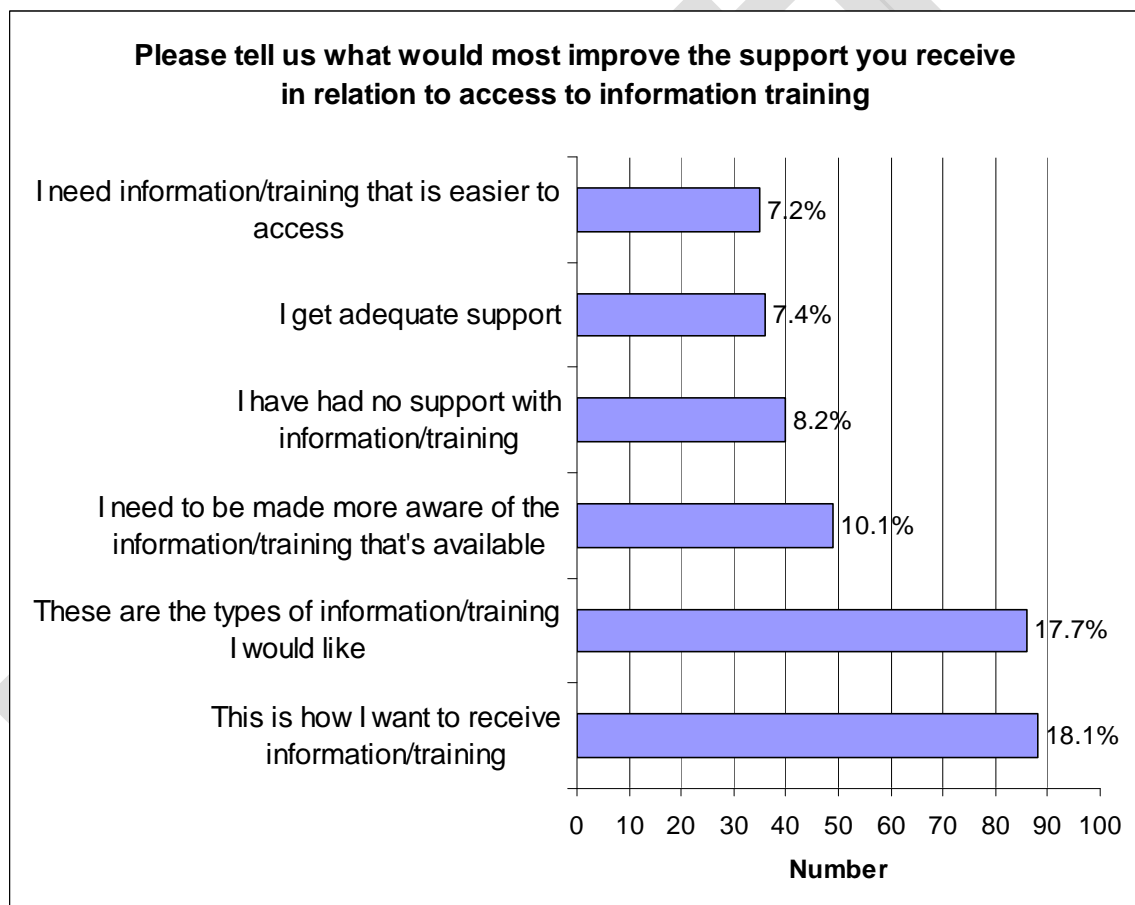


<b>Please tell us what would most improve the support you receive in relation to being respected as an expert partner in care</b>		
	<b>Number</b>	<b>Percentage</b>
<b>Listening to me and taking my views into account</b>	104	23.7%
<b>I already feel respected</b>	61	13.9%
<b>Recognising my support needs as a carer</b>	41	9.4%
<b>Better sharing of information between carers and professionals - working together</b>	32	7.3%
<b>I receive no or very little support</b>	29	6.6%
<b>Kept informed of decisions about care or changes</b>	23	5.3%
Being asked for my views and making decisions with professionals	17	3.9%
Recognition of the contribution of carers	16	3.7%
Respite/having time to myself	14	3.2%
Clear, single contact for queries and advice	13	3.0%
More money	12	2.7%
Improved communication between paid staff	7	1.6%
Better public understanding and awareness of the role of carers	4	0.9%
An emergency number to get help at short notice	4	0.9%
Training and guidance in caring	3	0.7%
Training for staff to help them understand carers	2	0.5%
Misc	56	12.8%
<b>Total responses</b>	<b>438</b>	<b>100.0%</b>

**Q1b**

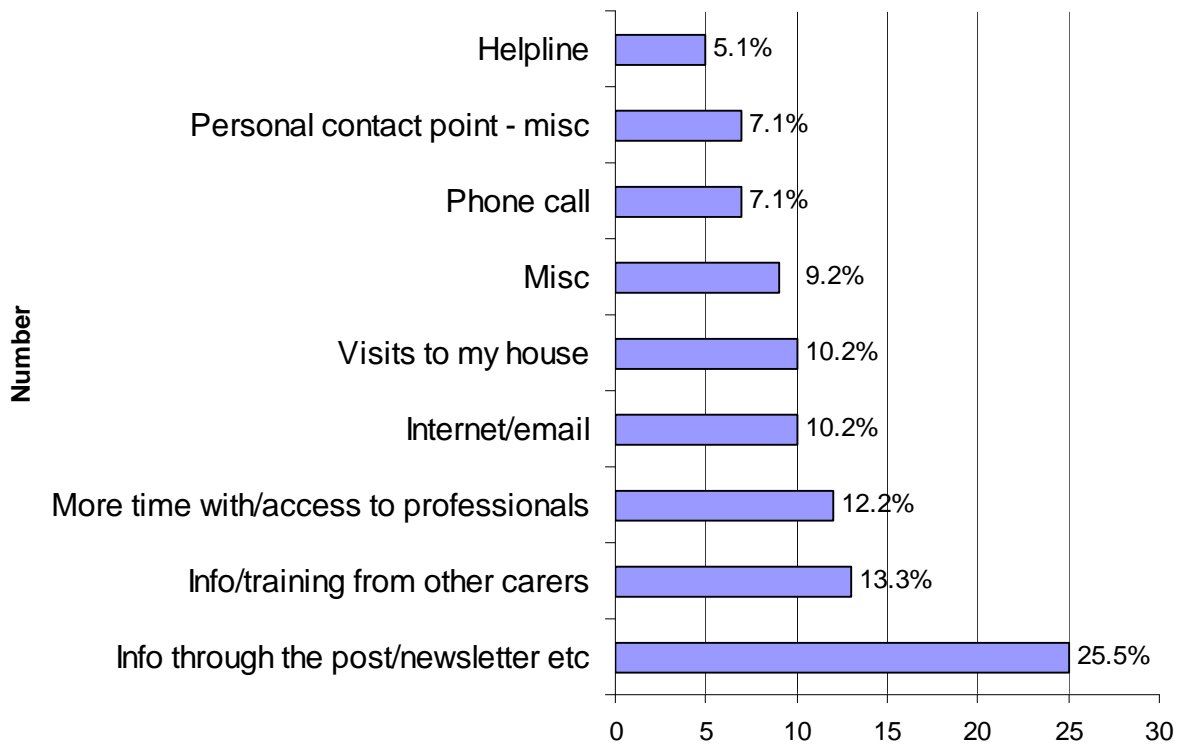
**Carers should have easy access to information and training to help them as carers**

Q1.b.						
<b>Carers should have easy access to information and training to help them as carers</b>	<i>very important</i>	<i>Important</i>	<i>neither important nor not important</i>	<i>not important</i>	<i>not at all important</i>	<i>na</i>
	562	264	45	8	5	36
884 responses = 100%	63.6%	29.9%	5.1%	0.9%	0.6%	



<b>Please tell us what would most improve the support you receive in relation to access to information and training</b>		
	<b>Number</b>	<b>Percentage</b>
<b>This is how I want to receive information/training (expanded in graph below)</b>	88	18.1%
<b>These are the types of information/training I would like</b>	86	17.7%
<b>I need to be made more aware of the information/training that's available</b>	49	10.1%
<b>I have had no support with information/training</b>	40	8.2%
<b>I get adequate support</b>	36	7.4%
<b>I need information/training that is easier to access</b>	35	7.2%
I don't need info/training now	26	5.3%
I get my information/training from Carers' groups/organisations	22	4.5%
I would like access to courses/training	15	3.1%
I need support to allow me time out to learn/train	14	2.9%
Any training must be local/transport provided	14	2.9%
I would like a single, simple point of contact for information	9	1.9%
I particularly want to know when new information is available	6	1.2%
Misc	46	9.5%
<b>Total</b>	<b>486</b>	<b>100.0%</b>

### This is how I want to receive information/training

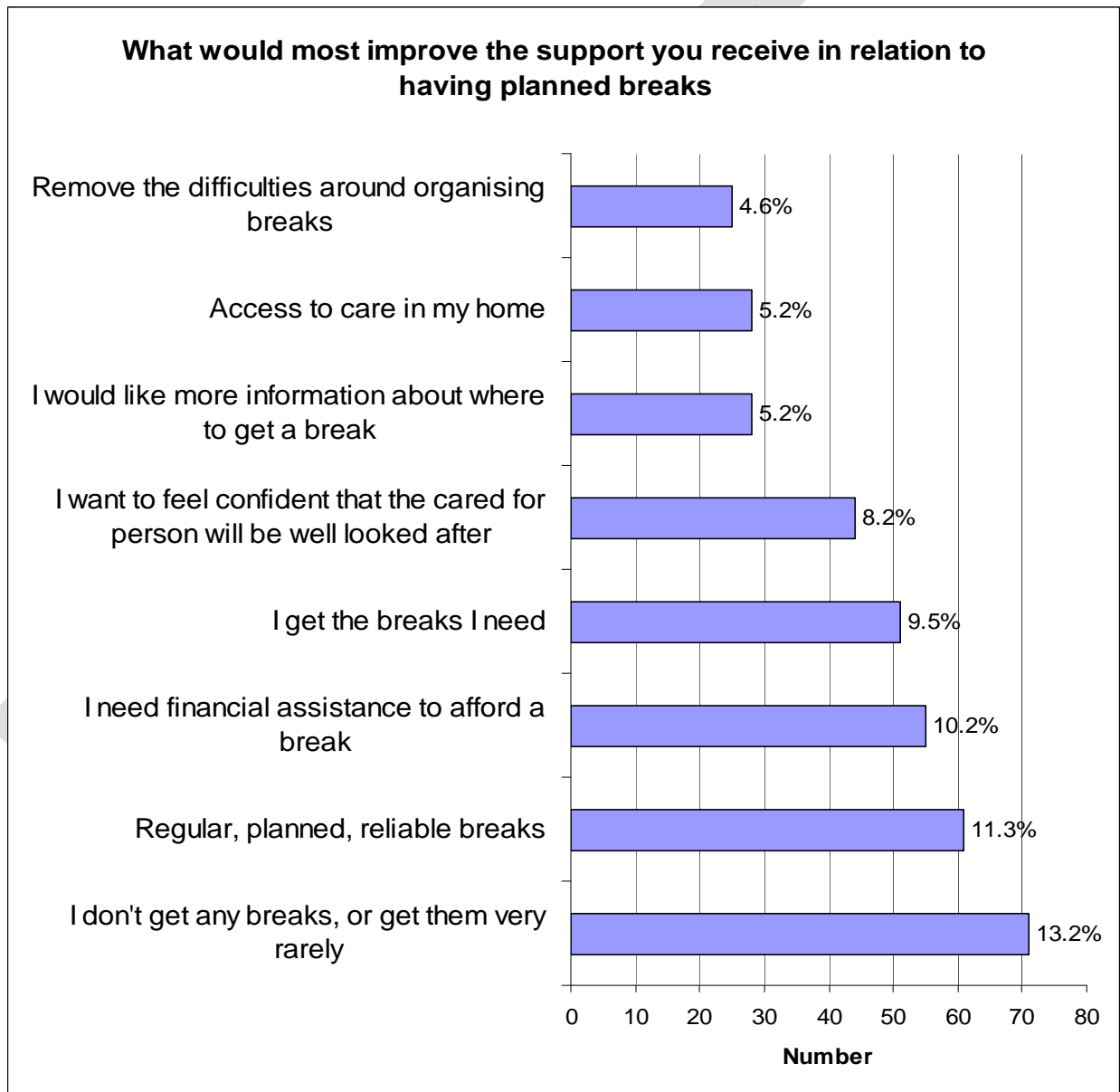


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**Q1c**  
**Carers should have more planned breaks**

Q1c						
	<i>very important</i>	<i>Important</i>	<i>neither important nor not important</i>	<i>not important</i>	<i>not at all important</i>	<i>na</i>
<b>Carers should have more planned breaks</b>	496	270	71	16	6	61
859 responses = 100%	57.7%	31.4%	8.3%	1.9%	0.7%	

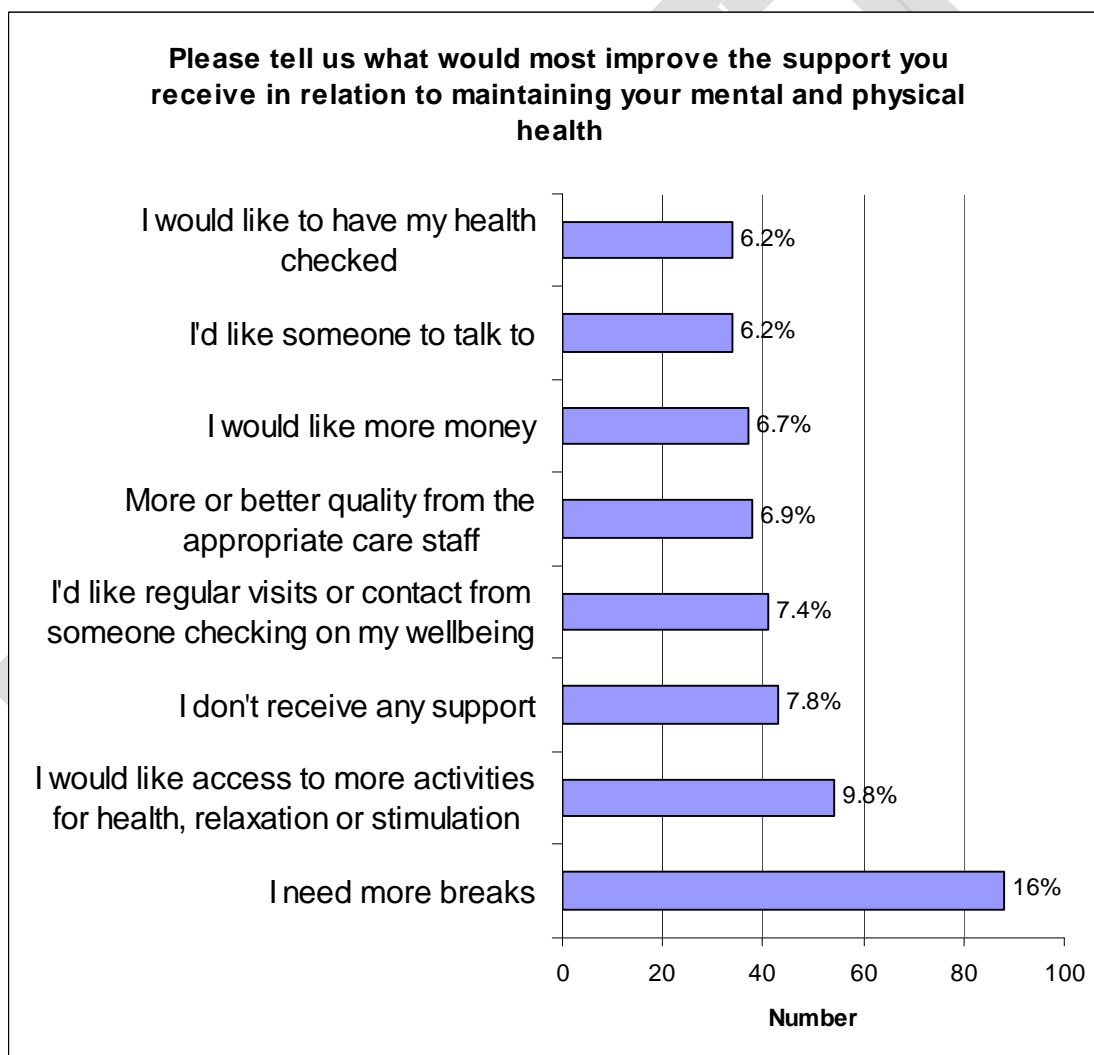


<b>What would most improve the support you receive in relation to having planned breaks</b>		
	<b>Number</b>	<b>Percentage</b>
<b>I don't get any breaks, or get them very rarely</b>	71	13.2%
<b>Regular, planned, reliable breaks</b>	61	11.3%
<b>I need financial assistance to afford a break</b>	55	10.2%
<b>I get the breaks I need</b>	51	9.5%
<b>I want to feel confident that the cared for person will be well looked after</b>	44	8.2%
<b>I would like more information about where to get a break</b>	28	5.2%
<b>Access to care in my home</b>	28	5.2%
<b>Remove the difficulties around organising breaks</b>	25	4.6%
Access to residential care	23	4.3%
Short breaks to do personal things	22	4.1%
I would like support to take breaks at short notice	12	2.2%
I would not take a break	12	2.2%
Access to a holiday	11	2.0%
Access to breaks together (carer and caree)	9	1.7%
I don't need a break/support	8	1.5%
Support from other carers	2	0.4%
Misc	76	14.1%
<b>Total</b>	<b>538</b>	<b>100.0%</b>

**Q1d**

**Carers should have support to help stay mentally and physically well**

Q1 d						
<b>Carers should have support to help stay mentally and physically well</b>	<i>very important</i>	<i>Important</i>	<i>neither important nor not important</i>	<i>not important</i>	<i>not at all important</i>	<i>na</i>
	615	227	33	2	5	38
882 responses = 100%	69.7%	25.7%	3.7%	0.2%	0.6%	



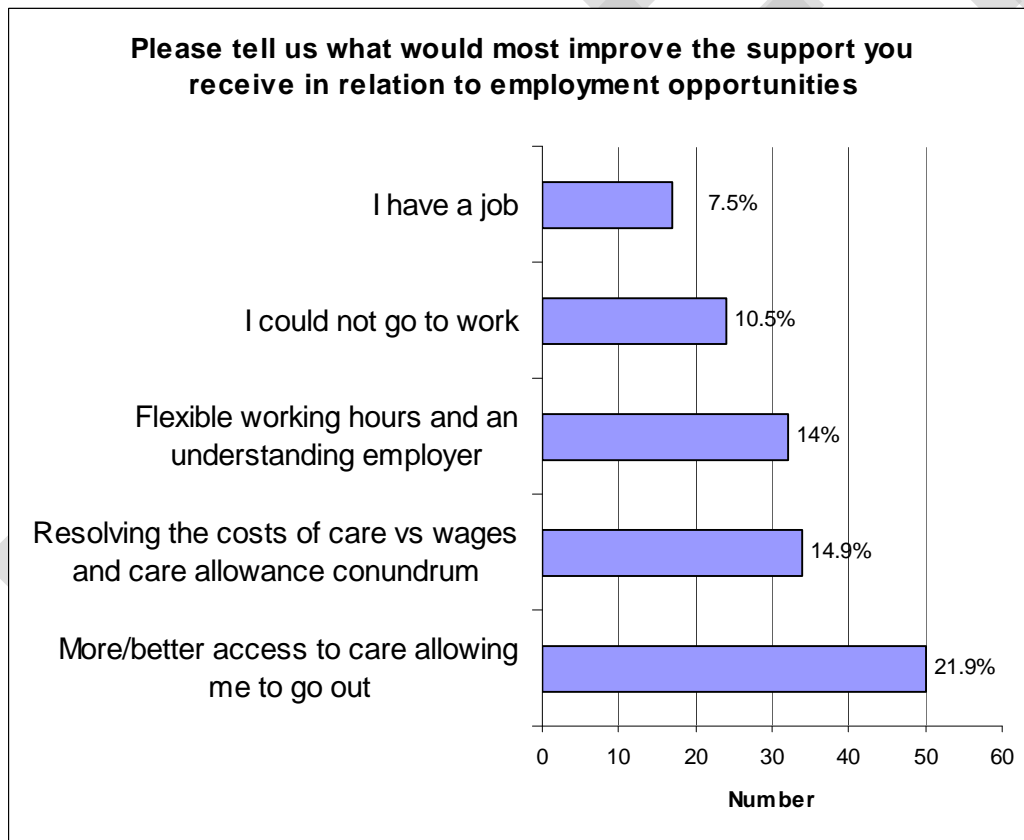
<b>Please tell us what would most improve the support you receive in relation to maintaining your mental and physical health</b>		
	<b>Number</b>	<b>Percentage</b>
<b>I need more breaks</b>	88	16.0%
<b>I would like access to more activities for health, relaxation or stimulation</b>	54	9.8%
<b>I don't receive any support</b>	43	7.8%
<b>I'd like regular visits or contact from someone checking on my wellbeing</b>	41	7.4%
<b>More or better quality from the appropriate care staff</b>	38	6.9%
<b>I would like more money</b>	37	6.7%
<b>I'd like someone to talk to</b>	34	6.2%
<b>I would like to have my health checked</b>	34	6.2%
I get enough support	25	4.5%
I'm fine	24	4.4%
I would like counselling or therapy	21	3.8%
I'd like support from other carers	17	3.1%
I'd like a dedicated helpline for emergency support and general advice	15	2.7%
Practical support (misc)	15	2.7%
I'd like information about what's available	12	2.2%
Help around the house	5	0.9%
Transport	3	0.5%
Misc	45	8.2%
<b>Total</b>	<b>551</b>	<b>100.0%</b>

**Q1e**

**Carers should have support to help them if they choose to either remain in, or return to employment**

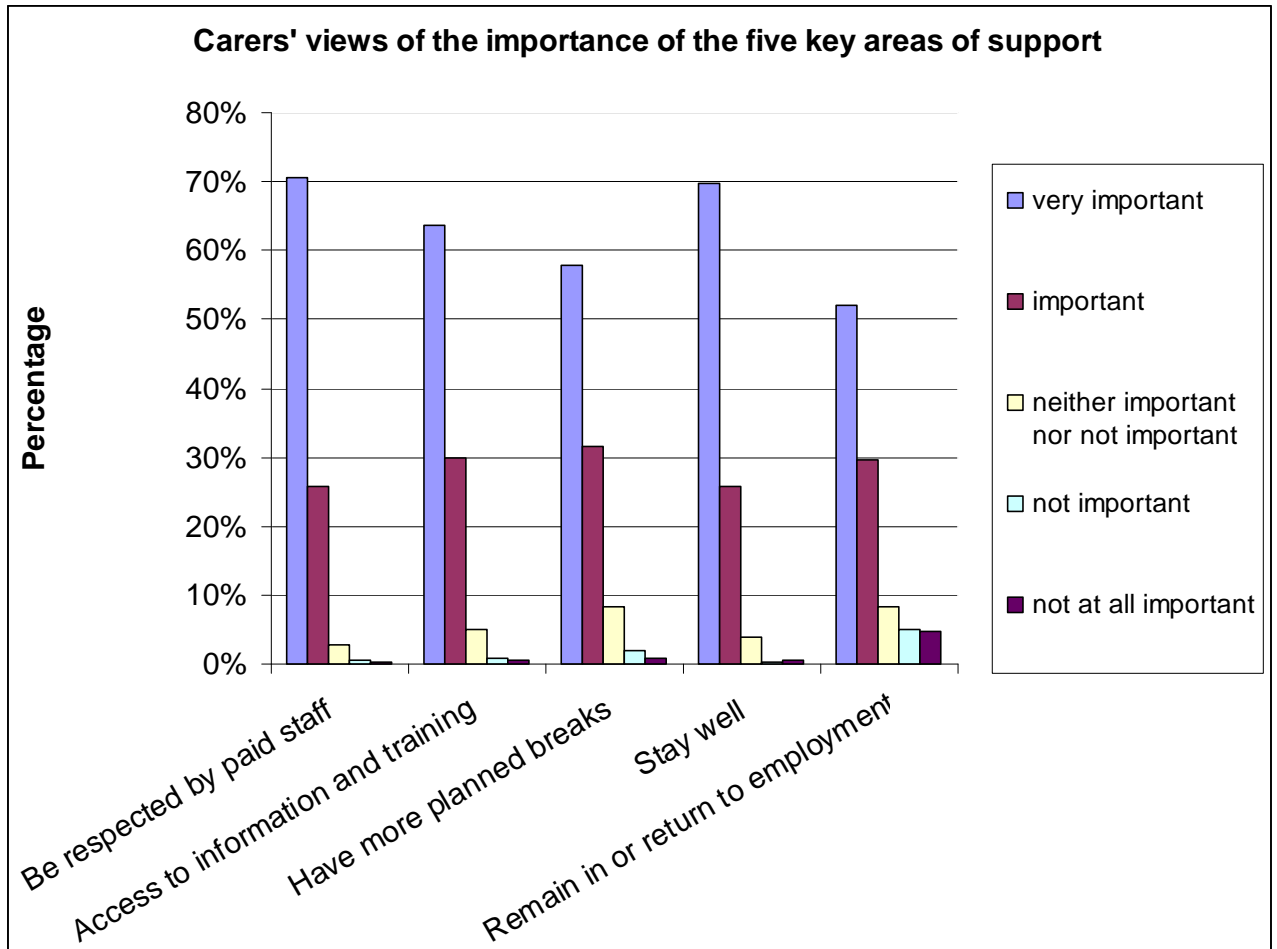
Q1 e						
<b>Carers should have support to help them if they choose to either remain in, or return to employment:</b>	<i>very important</i>	<i>Important</i>	<i>neither important nor not important</i>	<i>not important</i>	<i>not at all important</i>	<i>na</i>
	400	228	64	38	37	153
767 responses =100%	52.2%	29.7%	8.3%	5.0%	4.8%	

NB note large number of blanks (n/a) due to half of total respondents being older than 65 i.e. beyond working age.



<b>Please tell us what would most improve the support you receive in relation to employment opportunities</b>				
	<b>Number</b>	<b>Percentage</b>	<b>Number</b>	<b>Percentage</b>
<b>More/better access to care allowing me to go out</b>	50	12.1%	50	21.9%
<b>Resolving the costs of care vs wages and care allowance conundrum</b>	34	8.3%	34	14.9%
<b>Flexible working hours and an understanding employer</b>	32	7.8%	32	14.0%
<b>I could not go to work</b>	24	5.8%	24	10.5%
<b>I have a job</b>	17	4.1%	17	7.5%
<b>More information about support and advice for returning to work</b>	14	3.4%	14	6.1%
<b>I would like training</b>	10	2.4%	10	4.4%
<b>There is no support available</b>	10	2.4%	10	4.4%
<b>Day centres to stay open longer</b>	7	1.7%	7	3.1%
<b>Misc</b>	30	7.3%	30	13.2%
<b>Retired or n/a</b>	184	44.7%		
<b>Total</b>	<b>412</b>	<b>100.0%</b>	<b>228</b>	<b>100.0%</b>

**At a glance, full results for quantitative question.**

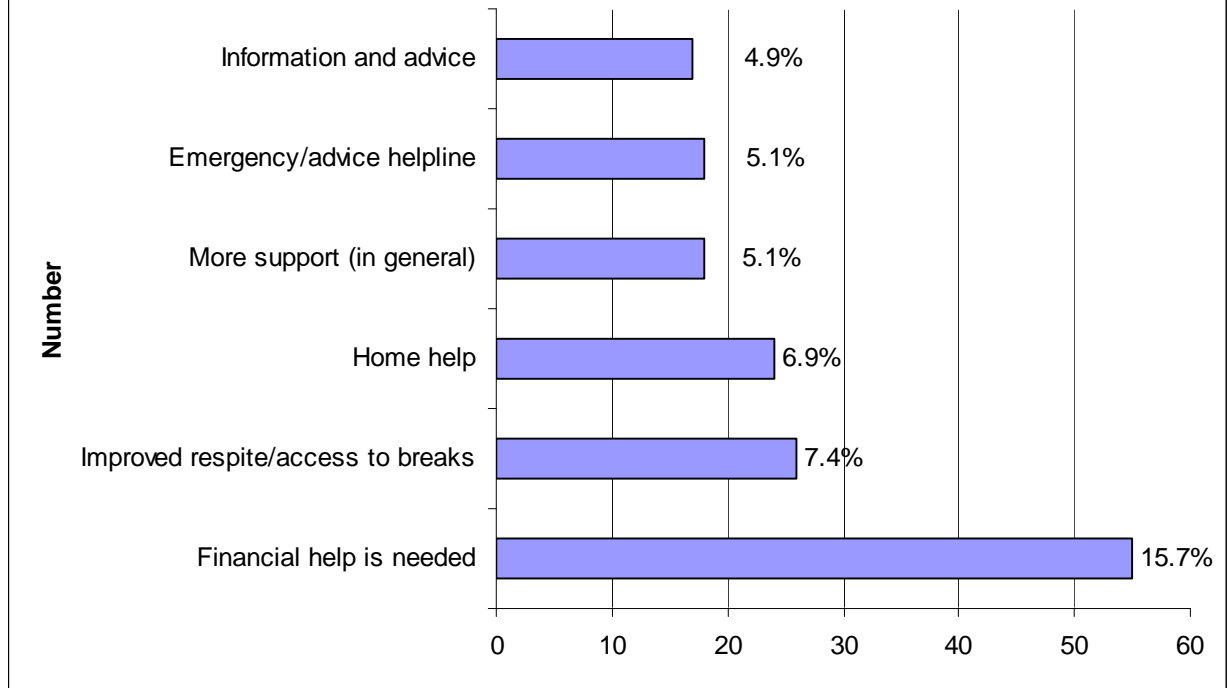


<b>In order...</b>	
<b>Very important</b>	
Carers should be respected by paid staff as expert partners in care	70.5%
Carers should have support to help stay mentally and physically well	69.7%
Carers should have easy access to information and training to help them as carers	63.6%
Carers should have more planned breaks	57.7%
Carers should have support to help them if they choose to either remain in, or return to employment:	52.2%
<b>Very important or important</b>	
Carers should be respected by paid staff as expert partners in care	99.5%
Carers should have support to help stay mentally and physically well	95.5%
Carers should have easy access to information and training to help them as carers	93.4%
Carers should have more planned breaks	89.2%
Carers should have support to help them if they choose to either remain in, or return to employment:	81.9%
<b>Not important or not at all important</b>	
Carers should have support to help them if they choose to either remain in, or return to employment:	9.8%
Carers should have more planned breaks	2.6%
Carers should have easy access to information and training to help them as carers	1.5%
Carers should be respected by paid staff as expert partners in care	1.0%
Carers should have support to help stay mentally and physically well	0.8%



<b>Q2</b>		
<b>Are there other types of support you would like that are not mentioned in Q1</b>		
	<b>Number</b>	<b>Percentage</b>
<b>Financial help is needed</b>	55	15.7%
<b>Improved respite/access to breaks</b>	26	7.4%
<b>Home help</b>	24	6.9%
<b>More support (in general)</b>	18	5.1%
<b>Emergency/advice helpline</b>	18	5.1%
<b>Information and advice</b>	17	4.9%
More support from better trained staff	13	3.7%
Help with transport	12	3.4%
Emergency care options	12	3.4%
Chance to meet with other carers	10	2.9%
Regular visits	10	2.9%
Someone to talk to	10	2.9%
Making processes easier or fairer	10	2.9%
Practical help/adaptations	10	2.9%
Central contact point for support	9	2.6%
Choice for younger people	7	2.0%
Access to and support from GP	6	1.7%
Help to understand treatments and medicines	5	1.4%
Emotional support/counselling	4	1.1%
Social opportunities	4	1.1%
More opportunities for carer and caree to get out together	3	0.9%
More day centres/better availability	3	0.9%
I get enough support	3	0.9%
Home study opportunities	2	0.6%
Help with bathing	2	0.6%
Misc (comments which reflected personal concerns not shared by other respondents)	57	16.3%
<b>Total</b>	<b>350</b>	<b>100.0%</b>
NB 40 people said they had nothing to add here, while 530 people left this section blank (n/a). So, 570 people are not been included in these figures.		

**Are there other types of support you would like that are not mentioned in Q1?**



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## APPENDIX D:

### **CASE STUDY – INDIVIDUAL RESPITE PROVIDED BY A SUPPORT WORKER FOR CARER AND CARED FOR ACCORDING TO THEIR NEEDS**

This case study is an example of the work undertaken by the Older People's Community Health Team in South Wealden, funded by Carers Grant.

Mr H has advanced dementia 92 years of age.. Mrs H is 87 years of age and is the main carer. Mrs H does not want home care, she is reluctant to engage with any services but agreed to accept a Community Support Worker (CSW).

A CSW visited for 1 hour weekly to have a cup of tea and a chat, get to know the couple and understand their situation. After a few weeks, Mrs H asked the CSW if she could stay a bit longer so that she could do some gardening without her husband disturbing her activity. The CSW stayed for 2 hours. This continued for 4 weeks and was then reviewed through Care Programme Approach (CPA – this is the way mental health support is planned and monitored).

It was agreed that the next goal would be to take Mr H out of his home for an afternoon to give Mrs H a longer break. The CSW introduced Mr H to a social group in a local community centre. The first week the CSW stayed for the whole afternoon session, the second week the CSW stayed for an hour and returned to collect Mr H. The third week voluntary transport collected Mr H and the CSW popped into the session to check he was ok. Weeks 4, 5 and 6 were as week 3.

At week 6 the CPA review of Mr H's case and the outcome was that the CSW objective had been met, the Carer was now receiving an afternoon per week respite and at this time did not want any more support.

6 months later, through Mr H's CPA review it was noted that Mrs H was struggling with her husband's care needs and further respite was suggested. The CSW was re-introduced to engage Mr H in another community-based activity and encourage Mrs H to attend a Carers' Course, 'Coping and Caring with Loss in Dementia'.

This Course is over an 8 week period and the CSW collected Mr H from his community activity to give Mrs H time to get back from her course. At the next review, the CSW withdrew as the objective had been met; the Client was engaged in activities meaningful to him in the local community thus creating 6.5 hours respite weekly for the Carer. The client's case remained open to CPA and the situation monitored by the Care Co-coordinator.

7 weeks ago Mrs H informed the Care Co-coordinator that she was in need of support, as she had medical appointments to attend. The CSW was re-introduced and was able to take Mr and Mrs H to the outpatients' appointments. Mrs H had asked that the CSW "entertain" her husband whilst she was in her appointment, so the CSW took Mr H for a walk in the hospital gardens.

4 weeks ago Mrs H informed the Care Co-coordinator that she needed emergency surgery for cancer of the breast (the following week) and she would need 3 weeks' rest afterwards. A residential respite placement was identified for Mr H, and plans made for

the CSW to provide transport to and from the placement, and also to visit Mr and Mrs H during this period.

Mrs H disclosed that she was worried about packing her husband's suitcase, pointing out that he became challenging and aggressive as he did not have the capacity to understand the need for their separation or that it was a temporary arrangement. Support was given by the CSW who took Mr H out for coffee allowing Mrs H the time to pack his case.

Mrs H underwent her surgery and was discharged home knowing that her husband was safe and well and that she had the support of the CSW if she needed support, advice or just a chat. Mr and Mrs H were re-united last week after 3 weeks' separation and Mrs H attributes her speedy recovery to the speedy intervention of this carers' service.

The CSW is now providing telephone checks to Mrs H who says she is getting on fine and does not need any more help at this time. She continues to benefit from her 6.5 hours respite (2 afternoons) when Mr H attends the community groups introduced by the CSW.

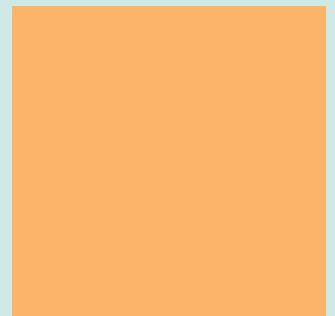
DRAFT



HM Government

# Carers at the heart of 21st-century families and communities

**"A caring system on your side.  
A life of your own."**



**Summary**



HM Government

# Carers at the heart of 21st-century families and communities

“A caring system on your side.  
A life of your own.”

## Summary



**DEPARTMENT FOR BUSINESS**  
**ENTERPRISE & REGULATORY REFORM**

department for  
**children, schools and families**



Government  
Equalities Office

Department for  
**Innovation, Universities & Skills**

# Preface



Caring for our relatives and friends when they are in need is a challenge that the vast majority of us will rise to at some point in our lives. At any one time 1 in 10 people in Britain is a carer – the majority of them, of course, still women. It is a testimony to the importance of families that so many of us are prepared to make the personal sacrifices that caring can involve in order to help our loved ones lead fulfilling lives even in the face of incapacity or disability. Our support and appreciation for carers is therefore not just fundamental to ensuring that those of us in need of care are able to receive it, but goes right to the heart of our values as a society and our ambition to create a fairer Britain.

Today, the demands both on our care system and on our carers themselves are greater than ever before – and they are set to continue to grow. So this strategy sets out the framework for developing support for carers not just as a one-off but as a progressive process of change over the next 10 years. It recognises the increasingly important role that carers play in our society alongside the wide variety of caring roles and the diversity of those within these roles, and it acknowledges that carers need more help and support than has been available in the past.

But above all this is a strategy based on the views and concerns of carers themselves. Through our Standing Commission on Carers and the many consultation events that we have held around the country, we are increasingly aware of the everyday challenges and obstacles that carers face.

Carers have told us they want a system that is on their side rather than one that frustrates them at every turn, including much more support to help them manage the twin demands of work and caring responsibilities. They want far more personalised support and greater scope to control and customise services, including in healthcare where identifying needs and ensuring prompt access to services can be so critical. And above all we recognise the need – repeated so many times throughout our

consultation – for better support for respite and short breaks. Too often carers are unable to access the kind of support which allows them to re-charge and renew themselves, and to address this we are taking immediate action to double our support for respite care over the next two years with an additional £150 million of new funding.

We have also heard and understood the request for us to do more to alleviate the financial hardships that all too many carers face, and as we look over the next year at the options for securing a better system of funding for all social care, we must also find the right approach to ensuring a fairer deal for our carers that provides financial support, particularly to those who face hardship.

These are the challenges we face, and this strategy is designed to help us meet them and to create a support system for carers that is fit for the 21st century. It is the start of a process rather than the end and I hope it will be welcomed by all carers as a platform from which we can build.

*Carole Rennie*





# Foreword by Secretaries of State

Every day 6,000 people take on new caring responsibilities, performing a crucial role in families and in their wider communities, by providing support, care and help with day-to-day tasks to those who otherwise would struggle to manage alone.

There is no fixed group that needs care. Support might be needed by relatives, friends, children, older people, people with disabilities or those who are ill. Caring has never been a sectional interest – everyone has the potential to become a carer, and it is likely that in the future more and more of us will. The number of people aged over 85 – the age group most likely to need care – is set to double over the next 20 years, affecting many more families. Traditionally caring has been seen as women’s work – and 70 per cent of it is still done by women but as our culture continues to change so too will this figure. Nine per cent of men now have caring responsibilities compared with 11 per cent of women. Caring is increasingly part of all our lives.

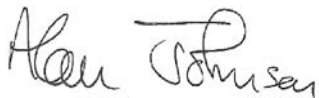
People who care do so because they want to help the people they care about, but often it means they end up juggling the support they give with other responsibilities, in a difficult balancing act. For many carers, looking after their own health, combining caring with work, getting access to training or simply having time to take a break and go away for a weekend can be a major challenge. People who provide a lot of care tend to have lower incomes, poorer health, and are less likely to be in work than their counterparts.

If carers are to have the same opportunities as everyone else in society, and to be able to have a life outside caring, we need to improve support and recognition for what they do. That means improving health and social care support, ensuring that carers are able to access education and leisure opportunities, and making sure that people with caring responsibilities have the chance to work flexibly so as to combine work with their caring roles. For the many children and young people who


support parents or other family members it means making sure that they are not providing unreasonable levels of care, and that they have the support they need to learn, to develop and to thrive.

This strategy sets out the action we plan to take, working with partners and, building on the progress made by our first ever carers' strategy, *Caring for Carers*, published in 1999.

Responding to the needs of the growing numbers of people who care is one of the major challenges we face as a result of the demographic changes underway today. We must work together using the 10-year framework set out in this strategy to ensure that this challenge is met.



Alan Johnson  
Department of Health



Hazel Blears  
Communities and  
Local Government




James Purnell  
Department for Work  
and Pensions



John Hutton  
Department for  
Business Enterprise  
and Regulatory  
Reform



Ed Balls  
Department for  
Children, Schools  
and Families



Harriet Harman  
Government Equalities  
Office



John Denham  
Department for  
Innovation, Universities  
and Skills

# Executive summary

Carers are at the heart of 21st-century families and communities. In a changing society most people are living longer, many are developing long-term clinical conditions and the vast majority have rising aspirations in terms of maintaining maximum independence and control over their own lives. Consequently, an increasing number of us may find ourselves taking on a caring role at some point in our lives.

Many people, mainly women, are now balancing work, childcare and caring for an ageing parent. Increasing numbers of older people often care for their partner while providing childcare for grandchildren, and parents of children with complex health needs know that they will be 'lifetime' carers. Furthermore, the positive shift to independent living and care at home, away from institutionalisation, will continue to require a greater contribution from carers. At the same time families are now frequently scattered across the world, couples are struggling to retain a positive work-life balance and in an ageing society, some older people are left isolated with little or no support from family or friends.



These changes mean that the needs of carers must, over the next 10 years, be elevated to the centre of family policy and receive the recognition and status they deserve.

Twenty years ago there was little or no recognition of the contribution and distinct needs of carers. Since the 1999 Prime Minister's Carers' Strategy there has been significant progress, including an annual Carers Grant to every local authority in England, the right to request flexible working and enhanced pension entitlements. Most recently, the *Aiming high for disabled children* programme will result in greatly enhanced support for families with disabled children.

## FACTBOX

### Funding to date and in the future

By March 2011, we will have invested over £1.7 billion for councils to use to support carers in a range of ways through the annual Carers Grant. This includes £25 million a year announced as part of the New Deal for Carers for emergency break provision.

We have also committed a further £22 million to cover the costs of the establishment of information services via a helpline and a training programme for carers and information service, and £3.4 million to directly support young carers through extended Family Pathfinders and support for whole-family working.

We are now investing over £255 million on new commitments as part of this strategy.

However, the next decade must lead to major and substantial change in the everyday lives of carers and the family members and friends they support. This new deal alongside the *Independent Living Strategy*, the social care reform programme set out in *Putting People First*, the long-term reform of the care and support system, NHS reforms, reforms within children's services and welfare reform, must ensure carers experience a system which is on their side rather than enduring a constant struggle so that they are supported to have a life of their own alongside their caring responsibilities.

Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

**By 2018:**

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- carers will be able to have a life of their own alongside their caring role;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity; and
- children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters* outcomes.

This is a shared vision and responsibility between central and local government, the NHS, the third sector, families and communities. It has been shaped by the thousands of carers, their advocates and front-line support staff, who have told us what matters most if we are truly to ensure that carers have the best possible quality of life and recognition that they deserve.

The action we will take to transform this from a vision to a reality over the next 10 years covers issues including breaks, income, information and advice, the workplace, training for the workforce, access to employment, emotional support, the health of carers and the specific needs of young carers.

Short-term changes will begin this year and be implemented over the next three years. Longer-term priorities are identified that will ensure we achieve our 2018 vision. We will consult with carers, their advocates and stakeholders on a timescale for their implementation, taking account of new advice and available resources.

The success of this transformational New Deal for Carers will depend on the commitment and vision of statutory, third and private sector agencies. In all cases they will need to engage with individual carers, the people that they support and carers' networks in a new way – which recognises that it is carers who are best placed to articulate their own aspirations as well as the emotional and practical realities of their caring experiences.

Over the next 10 years, it is carers who will judge the effectiveness of this strategy. It is they who will know whether they feel valued, respected and supported to have the best possible quality of life, often in difficult circumstances.

## Vision

Our vision is that by 2018, carers will be recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet the individuals' needs enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

This vision is shared by all central and local government, the voluntary sector and most importantly, carers themselves.

### **By 2018:**

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- carers will be able to have a life of their own alongside their caring role;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity;
- children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters* outcomes: to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being.

The strategy recognises that improving the support for the person being cared for is vital to improve the life of the carer.

To achieve the vision, we have made a number of commitments in the short term (up to 2011) and identified priorities which will be considered in the longer term.

## Introduction

Over the next 10 years, there will be significant changes in our society offering major challenges to services that support carers and those they care for. In a world where people survive with complex health conditions and live longer, the demand for care will continue to grow. Changes in traditional family life, for example, increased numbers of single households and geographical dispersion of families, will contribute to these challenges.

Since the release of the Prime Minister's Strategy on Carers in 1999 (*Caring about Carers*), carers have been a priority for governmental support. One of the main changes has been the introduction of the Carers Grant provided to councils in England so they can increase support for carers, particularly through the provision of planned breaks. The grant has provided over £1 billion of additional support to local councils since 1999.

We have supported legislation to give carers new rights, including the right to an assessment of their own needs, independent of the person they care for. When assessing carers, councils should bear in mind carers' need or wish to work, study or undertake leisure opportunities outside of their caring responsibilities.

The **Employment Act 2002** gave the right to request flexible working to parents of children under the age of 6 (or 18 if the child is disabled). The **Work and Families Act 2006** extended this right to employees who care for an adult.

In addition, legislation on equalities and the **Disability Discrimination Act(s)** recognises the right of people in society to equal citizenship, which will be of benefit to both carers and the people they care for and support.

### **The New Deal for Carers**

The 2006 White Paper *Our health, our care, our say* announced a New Deal for Carers made up of four parts, of which this strategy is the centrepiece.

- i. **A national information helpline and website, which will be launched in spring 2009.** Through one telephone number carers will access all the information they need directly, or be referred onto more appropriate support;
- ii. **A training programme for carers called Caring with Confidence, which will inform carers of their rights and the services available to them and help develop their advocacy and networking skills.** The training will be available on a face-to-face basis from August 2008, and on a distance learning basis, from December 2008;
- iii. **£25 million additional funding per year has been made available** to councils in England to provide emergency care cover;
- iv. **A major review of the 1999 Carers' Strategy.**

When developing the new strategy, we carried out a far-reaching consultation to identify those things that carers themselves said would make the most significant improvements to their lives. The total period for consultation lasted for six months and views were collected from over 4,000 people.

As well as the public consultation, we set up four Task Forces to examine the key problems carers face. The Task Forces focused on employment, equalities, health and social care and income.

### **Standing Commission on Carers**

We also established the Standing Commission on Carers in September 2007 to advise us on the development of the strategy and on matters it feels are relevant to improving support for carers in the longer term.



## Challenges, roles and responsibilities

### Definition of Carer

**A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.** We will carry out a full review and impact assessment of this definition to see whether it or another could be adopted across government. However, we recognise, of course, that there might still be certain trigger points before an entitlement to benefit or flexible working come into effect.

When discussing carers we also need to be aware that many carers do not identify themselves as such. For example, carers from many black and minority ethnic communities do not see themselves as carers, and are often unaware of the vital support they might be entitled to.

Caring can take a large number of forms and is undertaken by individuals from all walks of life. Importantly caring can, or is likely to, involve us all.

## Mutual caring

Elsie (88) lived at home with her daughter, Christine (60) who has a learning disability. They lived together all their lives and they did everything together. Christine was declared 'uneducable' at the age of 6 and Elsie was told to 'take Christine home and keep her happy'. Christine did not use any services until she was 40 when her dad had a stroke and Elsie found herself suddenly caring for two people. However, Christine really enjoyed the new activities and the contacts the services brought. As they both grew older, Christine did more and more things to help her mum as she found tasks like carrying the shopping increasingly difficult.

When Elsie was diagnosed with a terminal illness, both Elsie and Christine had full needs and carers' assessments as they were looking after each other. Services were offered to support Elsie when Christine was not at home, and to help Christine with things like cooking, cleaning and shopping for them both. Although Christine sometimes found it very difficult to care for her mum and watch her illness worsen, it was very important to both her and Elsie that they stayed together for as long as possible and she is proud of the care she provided while her mother was still alive. She says: *'Mum always looked after me and I'm glad I could look after her too because I know how she liked things done.'*

### CASE STUDY

## Caring for a sibling

Tim is 16 and has Asperger's Syndrome. His behaviour is often aggressive, unpredictable and destructive. Gemma, his sister who is 12, plays an important part in helping her mother manage his behaviour. She helps to "keep an eye on" Tim and occupies him when he comes home from the day centre. She helps when Tim has a dentist's or doctor's appointment by going with him and their mother and "doing it first", which makes it easier for Tim to carry out tasks or activities that are unfamiliar to him. Gemma gives up a lot of her free time to help with tasks such as cooking, shopping and cleaning, as her mother is often occupied with supporting Tim. However, Gemma is bullied at school. Gemma loves her brother but does not want to be involved in supporting him quite so much as she wants the bullying to stop and to "have a life".

### CASE STUDY

### The family role

The traditional source of care and support for those needing care is the family, and the best environment for the person being looked after is very often their own home. The strategy aims to support people and their carers in their own homes and communities wherever possible.

### Government's role

The Government has a key role in improving the health and well-being of carers and those they support. Its role is made up of four parts:

- providing leadership;
- monitoring implementation;
- setting the overall objectives; and
- helping to join up services.

## Wider society's role

Wider society must recognise the vital role of carers and the invaluable support they give both to individuals and to society as a whole.

Employers, in particular, have a key role to play in recognising the valuable contribution that carers can continue to make to the workplace and the economy in combination with their caring role.

## Integrated and personalised services

Carers told us that there is a lack of co-ordinated services for carers and that they would like services to be based on what they need and want. There should also be better joining up between services, managed by professionals who show a greater understanding of the role that carers play.

### **Our vision is that:**

Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.

## Personalisation

Personalisation is the new approach we have taken to ensure services are designed to fit individual needs and preferences. Its overall aim is that the state should help people to get services that are tailored to their individual needs. It emphasises the importance of the individual in making all the relevant decisions.

This vision for transforming social care is summed up in *Putting People First* – a formal agreement between central government and local service providers which also sets out our intention to improve information and strengthen advocacy and support services to help people and their carers work with all local services.

## Personal budgets

We have indicated that everyone using social care will in future have a personal budget, a term used to describe an upfront clear allocation of social care resources to individuals, and may choose to take that

as cash instead of social services. For carers, this new approach helps to ensure that service users have the flexibility to buy or influence the provision of services to meet their own needs and those of the carer. They can be used, for example, to provide practical support for the carer through purchasing services such as window cleaning or gardening, which perhaps the carer is unable to manage because of their caring responsibilities, or to provide appropriate breaks for the carer.

## Personal Budgets

Ashok is a Hindu male service user who only speaks Gujarati. Prior to receiving direct payments, he had been receiving help with personal care from a home care agency. However, the service was unsatisfactory and erratic, making planning impossible.

Additionally, the language barrier meant that his family had to take up concerns on his behalf as nobody from the agency spoke Gujarati. The family found it hard to take a break, and even though they had raised concerns with the homecare agency, no action was taken.

Now, Ashok uses his direct payment to employ someone from his local community who speaks his language. He also employs another lady who came recommended: she has learnt a few words in Gujarati to help communicate with him.

### CASE STUDY

## Information

Meeting carers' information needs is an important part of ensuring that people can receive personalised services. The New Deal for Carers includes an information service, providing full and easy to access information through a single national telephone number and website. This will come online in spring 2009.

We are also providing additional funding to enhance the information provision for carers focusing on easy to access (i.e. translated) and local information.

## Training

In 2008, we are launching the Caring with Confidence training programme to support carers. It will provide training for caring roles and will help carers to work better with professionals. It will inform carers of their rights, the services available to them, and help them link with other carers' networks, and gain confidence and skills in dealing with professionals.

## The NHS

Carers have called for closer working between the NHS, social services and themselves. To encourage this, we are establishing pilot sites to examine how the NHS can better support carers. This will involve:

- the active involvement of carers in diagnosis, care and discharge planning;
- greater support for carers at GP practices and hospitals; and
- closer working with councils and voluntary organisations.

## Voluntary sector provision

Many carers prefer to deal with voluntary organisations than statutory services. Both central government and a number of councils already support the voluntary sector. However, some areas have more developed voluntary sector services than others. We are therefore investing to expand the capacity and reach of the voluntary sector.

## Workforce

The workforce is vital to ensuring that carers and the people they care for get the services and support they need. In addition to other initiatives, we are funding a training and awareness raising programme for key professionals, from health to housing, to support carers.

## Longer term

It is important that over the next 10 years we continue to improve and increase local service provision for carers, with personalised and specialised carers' services tailored to carers' specific needs.

What we will be doing in the short term:

- carers' information helpline and website;
- funding to provide easy to access and local information for carers;
- new training programme for carers 'Caring with Confidence';
- pilots to look at how the NHS can better support carers;
- improving voluntary sector provision; and
- training and awareness raising for key professionals.

What we will consider in the longer term:

- access to specialist services in every community;
- possible new flexibilities for personal budgets;
- offering carers a lead professional; and
- sharing best practice with primary care trusts based on the NHS pilots.

## A life of their own

Carers told us that the provision of breaks and replacement care were among their highest priorities during the consultation.

### **Our vision is that:**

Carers will be able to have a life of their own outside of their caring role.

## Breaks

In giving carers a life outside caring we believe there should be a greater emphasis on the provision of planned breaks.

Breaks are seen as absolutely vital by carers. We have already committed to providing £370 million for short breaks for families with disabled children.

In addition, we will be investing a further £150 million over the next two years to fund more planned breaks for carers. This money, which will be made available from the NHS, is in addition to the Carers Grant, which stands at £224 million in 2008/09, which is provided to councils to support carers.

We are also investing in pilots to examine the cost-effectiveness and quality of flexible break provision.

## Headway Oxford Breaks for Carers – for carers of adults with acquired brain injury

Headway in Oxford supports adults with acquired brain injury, their carers and their families. It is a specialist service offering short breaks for carers, often at comfortable hotels across the country. It also provides a break away for the person being cared for to allow the carer a break at home.

Some brain-injured people suffer high levels of anxiety if separated from their carers overnight. For these carers to have peace of mind it is essential that they accompany the people they support on the break. Headway makes sure that the carers have as much time off as possible over the weekend. Such breaks offer mutual support for carers. Brain injury is an often misunderstood condition and carers of people who are brain-injured rarely meet people who understand their particular problems. Friendships formed during these breaks can help during the rest of the year.

**CASE STUDY**

### Technology

Technology can play a major part in giving carers peace of mind and in doing so provide space that they can call their own. One example of new technology that promotes independent living and so reduces the stress placed on carers is Telecare – various sensors placed around the home which trigger alarms at the sign of unusual activity such as leaving the gas on or leaving the front door open for prolonged periods at night.

### Housing, leisure and transport

Decent housing makes a critical contribution to the value and effectiveness of the health and care systems. The Housing Strategy aims to relieve some of the burden from carers by taking housing problems out of the equation.



Financial constraints placed upon carers because of their caring roles often prevent them from accessing local services. We are encouraging local authorities to share good practice on discounts for leisure and transport facilities for carers.

## London Borough of Hackney – Carer's card

The London Borough of Hackney offers resident carers an 18-month card that provides discounts at over 50 local businesses in Hackney. In addition, carers can enjoy concessionary rates for use of swimming, gymnasium and a number of other leisure centre facilities. There are plans to expand the scheme further with libraries such as offering extended borrowing times and waiving fees.

CASE  
STUDY

What we will be doing in the short term:

- increased funding for breaks from caring for carers;
- pilots to assess the quality and cost-effectiveness of breaks; and
- sharing best practice in terms of supporting carers across councils.

What we will consider in the longer term:

- possible further increases to break provision;
- share best practice about quality and innovative approaches to breaks; and
- look at how councils work with voluntary organisations.

## Income and employment

Improving the financial position of carers was raised as an important consideration for carers during the consultation. In addition, carers told us that they wanted the opportunities to combine paid employment with their caring role.

### **Our vision is that:**

Carers will be financially supported so that they are not forced into financial hardship by their caring role.

## Income

Since 2001, we have introduced a number of measures to help improve financial support for carers. Depending on their circumstances, carers also have access to the full range of social security benefits. A carer entitled to Carer's Allowance may also qualify for other benefits, such as Income Support or Pension Credit with additions to the standard rate to recognise their caring responsibilities. Parent carers may also be eligible for tax credits.

For lower income carers, we raised the carer premium in the income-related benefits in 2001 by £10 over and above the normal annual increase in line with prices. We also removed the 65 age limit for new claims to Carer's Allowance from 2002.

From 2010, we are also introducing a National Insurance carer's credit for carers providing at least 20 hours of weekly care to recognise their need to protect their rights to State Pension. Carers entitled to Carer's Allowance accrue a National Insurance credit for each week that they meet the Carer's Allowance entitlement conditions.

### *Reviewing carers' benefits*

We acknowledge that in the long term the current structure of benefits for carers needs to be reviewed. However, we need to do this within the context of wider welfare reform and the review of the care and support system rather than in isolation so that we can create a flexible system that reflects the diversity of carers and their needs that is simple and aligned across the benefit system.

## Employment

Carers' income can be greatly improved if they can combine working with caring – a common wish for many carers. We want to enable all carers who wish to return to work to be able to do so. To help achieve this ambition the **Work and Families Act 2006** extended the right to request flexible working to employees who care for an adult. An awareness raising campaign about this right for employers and carers will shortly be launched. This right includes only those who are caring for a spouse, partner, civil partner, relative, or who live in the same home as the person they are caring for. We are reviewing how to include more carers within the scope of this law.

## Working carer who is supported in paid employment

Clive is a police sergeant. He is 46 years old and has cared for his wife Lucy, who is 52, for the past five years. They live together and he showers and dresses her, deals with her arrangements and plans and organises her activities for her. Clive works a four-day week and has compressed hours, meaning he works a full working week in those four days. This makes it easier to plan hospital appointments for Lucy and to do other tasks that make up his activities as a carer. He is grateful to his employer for the flexible working package they have offered him and they benefit from the skills and experience he is still able to bring to the force.

### CASE STUDY

A carer-specific programme will be introduced at Jobcentre Plus that will improve the help and advice available to carers who wish to re-enter the job market by:

- improving information about flexible job vacancies in Jobcentre Plus job banks;
- introducing Care Partnership Managers in every Jobcentre Plus district;
- introducing specialist training for Jobcentre Plus advisers who work with carers;
- funding replacement care for those who are participating in approved training;
- ensuring carers have access to appropriate employment programmes; and
- investigating the feasibility of providing return to work support through voluntary organisations.

### **Employers**

Engaging with employers is absolutely vital to ensuring carers can combine paid employment with caring. We are working with business to produce a good practice guide that will emphasise the business case for employing carers.

## Flexible working at BT

75 per cent of BT's 100,000-strong workforce work flexibly. The company has identified the following benefits:

- productivity gains averaging 21 per cent for employees working flexibly;
- cost savings, including £1 billion in office costs and equipment for home workers;
- greater customer satisfaction – BT's customers rate the quality of service has risen by 5 per cent since flexible working was introduced;
- more creativity and energy because flexible working produces twice as many new ideas;
- reduced sick leave – less than three days a year for home workers
- staff turnover is less than 4 per cent;
- a trust-based relationship with employees that is "worth its weight in gold";
- reduced CO<sub>2</sub> emissions and traffic nuisance – flexible working saves 12 million litres of fuel a year.

Lisa Crowley, a PA to a BT senior director, lives with and cares for her elderly mother who has severe arthritis. She juggles successfully the demands of work and caring thanks to an understanding line manager and the chance to work occasionally from home. "It's sometimes a struggle but the rewards are worth it," says Lisa. "What is reassuring is that I don't feel I have to justify any absence. My manager and colleagues are aware of my situation, and they don't mind if I have to use the phone in office time for personal calls. This makes such a difference to me and my mum."

CASE STUDY

## Training and skills

We are committed to ensuring that training is provided in a flexible manner so that it can be fitted around caring responsibilities.

We are developing an adult advancement and careers service that will offer advice and guidance as well as a Skills Health Check. This will form the basis of an action plan to help an individual progress back into learning and work.

What we will be doing in the short term:

- review flexible working practices for carers;
- an awareness raising campaign for employers and carers about flexible working;
- a good practice guide for employers around supporting carers;
- improving the support offered to carers by Jobcentre Plus; and
- ensuring skills training is provided in a flexible manner.

What we will consider in the longer term:

- reviewing structure of benefits in the context of wider benefit reform.

## Health and well-being

Carers told us that they should not have to neglect their personal health needs because of their caring role. Furthermore, as partners in care, they should be treated with dignity and respect, both as carers and individuals in their own right.

### **Our vision is that:**

Carers will be supported to stay mentally and physically well and treated with dignity.

### *Annual health checks for carers*

We are piloting annual health checks for carers that will detect emerging health problems from an early stage. If successful, these pilots may be extended more widely.

### ***Emotional support***

Carers are more likely to experience high levels of psychological distress, including anxiety, depression and loss of confidence and self-esteem than non-carers.

In addition to the psychological therapies currently being rolled out across the country, we are considering giving priority to funding national projects providing emotional support to carers.

### ***Training for GPs***

The Princess Royal Trust for Carers, in partnership with the Royal College of General Practitioners (RCGP), has already published a good practice guide highlighting the needs of carers and carers' health.

We will work with the RCGP to build on this to develop, pilot and evaluate a training programme for GPs to help them better understand carers' needs. The pilots could lead to a national training programme.

### ***Expert partners in care***

Key to treating carers as partners in care is ensuring they are equipped with the relevant information to the care and needs of the person they support in the form of 'information prescriptions'. These should go some way to ensuring that carers have the information they need to act as partners in care. The forthcoming Next Stage Review of the NHS will echo the importance of carers being treated as expert partners in the NHS.

What we will be doing in the short term:

- piloting annual health checks for carers;
- GP training pilots; and
- improving emotional support for carers.

What we will consider in the longer term:

- developing a full training package for GPs;
- rolling out annual health checks for carers nationally;
- replacement care to cover hospital appointments;
- discussing with GPs and other health professionals how they can give greater support to carers; and
- providing more information sharing between carers and professionals, especially where mental capacity is an issue.

## Young carers

Young carers were particularly concerned about gaps in support around the family and the person they care for. They also worry about their own problems – missing out on the opportunities other young people have.

Children should not have to take on inappropriate types and levels of caring, which can affect school attendance, emotional and physical well-being and longer-term life opportunities.

### **Our vision is that:**

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

### ***Targeted support for young carers***

Across the UK dedicated young carers' projects have increased from 110 in 1999 to some 350 current projects. They are now in contact with around 25,000 young carers.

We will commission further research to assess the types of project-based support available to identify best practice over the next year.

We will invest in a new programme to make sure that what we learn from our current young carers' projects helps to influence emerging programmes, including Extended Schools and targeted youth support, so that local areas can strengthen the range and quality of support they give.

## Young Carers Forum

The Children's Society, in partnership with The Princess Royal Trust for Carers, has facilitated the establishment of the first National Young Carers Forum for England. Members of the Forum have made a DVD called "Listening to Young Carers", in which young people talk about the issues they face and share solutions that will help improve their lives.

**CASE  
STUDY**

### Universal services

Although some schools and colleges offer high quality support there is still much to be done.

We will invest in a new programme of action as part of the Healthy Schools Programme to embed greater awareness of and support for young carers.

We are also funding new training materials tailored for GPs and hospital discharge teams, complementing other training and awareness raising initiatives planned for GPs under this strategy.

We will also provide funding to increase awareness of caring and the issues it raises across children's settings more generally.

### Whole family support

Young carers responding to the consultation made clear that better support for their family and the person cared for was the priority.

We have already invested £3 million in our Extended Family Pathfinder programme for young carers, which looks specifically at how to build better, more preventative forms of support around families who might be at risk of relying on the care of a child.



We have provided £600,000 to The Children’s Society and The Princess Royal Trust for Carers to develop guidance on working with the family as a whole, and establishing good practices in relation to young carers.

We will invest £4 million over two years to expand our Extended Family Pathfinder programme, enabling a further 12 to 13 areas to participate.

We will also invest £1 million through voluntary projects to enable them to contribute to our prevention agenda.

We will invest in an expanded programme of local and regional training for staff in local services on ‘whole family working’. The training will be particularly targeted at teams working in mental health and substance misuse.

What we will be doing in the short term:

- more support for schools to help them in their support for young carers;
- awareness raising on carering and the issues it raises across children’s settings more generally;
- training materials for health professionals;
- preventing children from falling into inappropriate caring–action to help build better, more preventative support;
- action to ensure better joined-up support around the family; and
- training for staff in local services on whole family working.

What we will consider in the longer term:

- what more can be done, on the basis of ongoing pilots and research, to improve protection for young carers.

## Implementation

We will put robust arrangements in place to oversee progress in implementing the strategy over the next 10 years.

We are establishing a cross-departmental programme board that will work with national, regional and local partners to ensure the strategy is delivered at every level. It will also ensure all the necessary preparatory

work is undertaken to support delivery of the commitments made for the next two years, as well as taking forward the longer-term proposals.

The Standing Commission on Carers will also play a key advisory role in advising on progress in implementing this strategy and will advise Government on ways that carers can continue to be supported as society evolves and changes. It will publish an annual report.

### ***Maintaining a regional and local overview***

Regionally and locally, progress will be monitored within agreed performance frameworks, and we will actively encourage a stronger multi-agency approach in delivering the strategy.

### ***Surveying carers' experiences***

We are developing a survey for councils to assess carers' experiences, and therefore help them to improve the quality of services. At a national level, we will include a section on carers in an "omnibus survey" this year.

The 2001 Census question helped us collect reliable data about carers. Hence we have ensured that a question on carers is also included in recommendations to Parliament for the 2011 Census.

What we will be doing in the short term:

- establishing a cross-government programme board;
- including carers in the larger omnibus survey;
- recommending the inclusion of a carer's question in the next Census;
- undertaking a national carer's experience survey.

What we will consider in the longer term:

- reviewing performance measures to focus on carers' experiences.



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