



REFRESHING THE NATIONAL CARERS STRATEGY

Call for Evidence

The previous Government's national Carers Strategy – *Carers at the heart of 21st century families and communities* – was published in June 2008. It set out a vision 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, while enabling the person they support to be a full and equal citizen.'

Ministers and the Standing Commission on Carers believe that the vision in the Carers Strategy holds good. As part of the process for informing the Spending Review, the Government must prioritise its actions for the next four years to ensure maximum value for money in the context of the current economic climate and the Government's top priority of reducing the national deficit.

The Government is therefore 'refreshing' the Carers Strategy with a view to producing, before the end of this year, a clear plan of action for 2011 to 2015. This will set out the key activities upon which the Government – working in partnership with Local Authorities, the NHS, employers, the voluntary sector, local communities and carers – can focus from April 2011 onwards, within the context of the 'Big Society' and the capacity of the community to support and empower people. The Government is not seeking to re-write the Carers Strategy.

The Government is keen to seek your views now on the key priorities – supported wherever possible by evidence of good practice – on what will have the greatest impact on improving carers' lives in the next four years. The deadline for responses is 20 September 2010.

The Government appreciates that this is a tight timescale but it is a necessary one if the Government is to help inform decisions in the light of the Spending Review and influence planning by Local Authorities, the NHS and others for April 2011 onwards.

This document is for you to use to give your views. It sets out the main ambitions of the previous Government's Carers Strategy, and asks what you believe are the top priorities on which we should focus in the next four years, and what evidence (including, where relevant, personal experience of what has worked well and proved most cost-effective) you can detail to support those assertions.

Some important points to note:

1. The Government recognises that the issue of carers' benefits is important and will consider this area separately under plans to simplify and modernise the benefit system. In this call for evidence, we are interested to hear about support other than cash benefits that would help to improve carers' lives.
2. The consultation on the extension to the right to request flexible working for all, referred

- to in the Coalition Government's Agreement, is separate to this call for evidence and will be launched by the Department for Business, Innovation & Skills (BIS) later in the year.
3. The Commission on the funding of care and support has recently been established to make recommendations to the Government on how to achieve an affordable and sustainable funding system for care and support, for all adults in England. The Commission will consider evidence from stakeholders including carers as part of its work and will set out how it will engage on this issue shortly.
 4. When submitting views on priorities, please be mindful that the present position with public finances makes it likely that there will need to be 'trade-offs' in order to determine the highest priorities.
 5. The Carers Strategy relates to health, social care, education and training in England, to benefits in Great Britain and to employment in the United Kingdom.

The outcomes identified for 2018 (as set out in the strategic vision of the Carers Strategy) are:

- 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.

Each of those outcomes is very important but the Government is seeking evidence on what actions are most likely to deliver them. **In your view, what are the priorities to focus on in the next four years?**

Coalition Government's Agreement

The Coalition Government's Agreement recognises the importance of carers to families and communities and sets out that the Government will look to provide support to carers particularly through:

- extending the roll-out of personal budgets to give people and their carers more control and purchasing power;
- using direct payments to carers and better community based provision to improve access to respite care;
- extending the right to request flexible working to all employees, consulting with business on how best to do so; and
- establishing a commission for long-term care which will consider how to ensure responsible and sustainable funding for long-term care.

NB: The points from the Coalition Government's Agreement are included for background purposes only. We are not seeking views from stakeholders on the Coalition Government's Agreement.

How the Government is distributing this document and collecting views

This call for evidence will build on the extensive consultation with carers undertaken by the previous Government in developing the Carers Strategy and all the evidence contained in it. The Government encourages all organisations responding to this call for evidence to seek and reflect the views of carers about priorities.

The following people and organisations are being asked to disseminate this document through their networks:

- Local Authority Chief Executives
- NHS Chief Executives
- Directors of Adult Social Services and Children's Services
- Association of Directors of Adult Social Services and Association of Directors of Children's Services – Carers Reference Group
- NHS Confederation
- Local Government Association
- Government departments
- Voluntary sector (including Carers UK, Crossroads Care, The Princess Royal Trust for Carers, Alzheimer's Society, Age UK, Mencap, Rethink, Macmillan, Disability Alliance, Counsel and Care, The Children's Society, National Young Carers Coalition, RADAR – The Disability Network, Disabled Parents Network, Council for Disabled Children, National Children's Bureau, Barnardo's, Contact a Family, National Black Carers & Carers Workers Network, The Afiya Trust and others)
- Care Quality Commission
- Equality and Human Rights Commission
- Employers for Carers
- Confederation of British Industry
- Federation of Small Businesses
- Employers Engineering Federation
- Institute of Directors
- British Chambers of Commerce
- Trades Union Congress
- UNISON
- Centre for International Research on Care, Labour and Equalities (Leeds University)
- Personal Social Services Research Unit

It is also available to download at the Department of Health website at:
http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_117249

Please forward this document to others who you think may wish to respond.

Summary of key milestones

- 20 September 2010 – deadline for responses to this call for evidence
- September - October 2010 – analysis of evidence received (involving Standing Commission on Carers)
- Autumn 2010 – publication of plan for 2011-2015 (after the outcome of the Spending Review is known)

If you wish to respond

Please complete the tables on pages 5-12 and either email your response to carerevidence@dh.gsi.gov.uk or post it to:

**Carers Evidence
Carers Strategy Team, Department of Health
Area 116, First Floor
Wellington House
133-155 Waterloo Road
London SE1 8UG**

Your contact details

Name of organisation / individual	Contact details
Donna O'Brien Social Policy and Campaigns Officer Parkinson's UK	Address: 215 Vauxhall Bridge Road London SW1V 1EJ Tel. no.: 020 7963 9307 Email: dobrien@parkinsons.org.uk

Freedom of Information

The Department of Health will manage the information you provide in response to this call for evidence in accordance with its Information Charter.

Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may be published in a summary of responses to this call for evidence and passed on, in summary form, to other Government departments.

Are you happy for your response, in summary form, to be passed by the Department of Health to other Government departments?

Yes / No (please delete as appropriate)

Are you happy for your response to be published in a summary of responses?

Yes

Are you responding: - *as a member of the public*

 - *as a health or social care professional*

 | - *on behalf of an organisation*

Equality Impact Assessment

An Equality Impact Assessment was conducted for the Carers Strategy when it was published in 2008. It is available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

Around 6 million people in the UK spend a significant proportion of their life providing unpaid support to family or friends. This can involve caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. The 2001 Census showed that, in England, there were 4.83 million carers (one in ten of the population), and two-thirds of carers of working age combine paid work and care. 58% of carers are women and over-65s account for around a third of all carers providing more than 50 hours of care a week. The Census also indicated that there were approximately 139,000 young carers in England.

The Government recognises that carers are not a homogenous group. Their caring role may develop gradually or it may be thrust upon them unexpectedly or suddenly. Although many carers are family members, others may be friends or neighbours providing a range of practical and emotional support. Demographic change and social mobility mean that many carers may live at a distance from the person to whom they provide support.

A growing number of carers (in particular parents of adult children with a learning disability or long-term condition) may be 'lifetime carers', with many carers providing support well into their later years. There are also inter-generational 'sandwich carers' (with multiple caring responsibilities) and carers who are themselves disabled. In addition, significant numbers of carers do not identify themselves as such (for example, cultural concepts of caring are not universally shared throughout communities in Britain).

Of the organisations listed on page 3 to which we are sending this call for evidence, the following will be particularly relevant in helping us to make sure, by disseminating through their networks, that it reaches as many carers as possible:

- The Afiya Trust
- Alzheimer's Society
- Barnardo's
- Carers UK
- The Children's Society
- Contact a Family
- Council for Disabled Children
- Counsel and Care
- Crossroads Care
- Disability Alliance
- Disabled Parents Network
- Equality and Human Rights Commission
- Macmillan
- National Black Carers & Carers Workers Network
- National Children's Bureau
- National Young Carers Coalition
- The Princess Royal Trust for Carers
- RADAR – The Disability Network

The Government will undertake a further Equality Impact Assessment in the autumn alongside the preparation of this action plan.

Your views on priorities (by outcome of the strategic vision of the 2008 Carers Strategy)

Parkinson's UK is pleased to have the opportunity to respond to this consultation. Approximately 120,000 people currently have Parkinson's in the UK. One in eight people are affected by the condition, through family and close friends, many of whom are carers. Nine out of ten carers for people with Parkinson's regularly look after a spouse or partner and nearly two thirds are "intensive" carers, spending 50 hours or more per week caring for that person. These people need access to high quality health and social care wherever they live. This is a key aim of Parkinson's UK Fair Care Campaign.

The consultation asks what are the key actions that will improve outcomes for carers, and deliver maximum value for money.

Firstly, by virtue of the unpaid care they provide, carers save the UK an estimated £87 billion in health and social care costs.¹ This is excellent value for money. Investment in carers' services offers long term savings. By increasing carers' wellbeing and access to work and training, savings are created for the state by reducing lost tax revenues, welfare benefits expenditure, residential care admissions, and healthcare spending on the carer. Carers are a prime example of where budget cuts will be a false economy. As the prime minister has said "Carers are a vital thread, and we pick at that thread at our peril."²

The Standing Commission on Carers, as the independent expert advisor, has published an initial report on progress with the Strategy (October 2009) but with both the Standing Commission and a Cross-Government Programme Board aiming to monitor delivery, there should be a substantial amount of evidence by now on which areas of the Strategy are underperforming and which projects are offering value for money. It is regrettable that this sort of analysis has not been published alongside the strategy refresh. However, it is clear that significant funding streams for carers are not reaching those for whom they are intended, due to a lack of accountability and close monitoring.

We are disappointed that the consultation limits a discussion on carers' benefits. These benefits are vital to carers and their ability to cope with their caring responsibilities. Moreover, the command paper, *21st century welfare*, contains no detail of how carers' benefits will be reviewed and modernised. Therefore there is little evidence that the issue is being addressed as a matter of urgency by policymakers elsewhere.

Parkinson's UK believes that addressing the needs of unpaid carers who support

¹ University of Leeds, on behalf of Carers UK, 2007

² Carers Week 2010

people with Parkinson's must be treated as a priority by local and national policymakers. This should be reflected through:

- Appropriate funding for carers benefits and services
- Clear targets for improving support
- National outcome measures to monitor the performance of local authority and NHS services.

Evidence from successive Parkinson's UK surveys show that measures in the ten year 1999 National Carers Strategy did not have significant impact. Concerted action is therefore needed to ensure the goals of the 2008 National Carers Strategy are achieved, particularly in the light of national statistics that show the numbers of carers providing "intense" care of over 50 hours a week has doubled in the last decade, to 1 million carers.³ We look forward to the publication of the full Survey of Carers in Households in England by the NHS Information Centre in December 2010.

In the meantime the first national user experience survey of adult carers in England, published by the NHS Information Centre in June 2010 provides useful evidence of carers needs. However, we would caution that this first survey is of adult carers already known to social services: many carers are "hidden" and do not contact social services for help.

Our supporting evidence is provided from our published member's survey of 2008 *Life with Parkinson's today* and the 2009 inquiry undertaken by the All Party Parliamentary Group on Parkinson's Disease *Please mind the gap: Parkinson's disease services today*. For brevity we refer to these as "our survey" and "the inquiry" in our evidence below. We also have evidence from focus groups we undertook with carers to develop our policy position published in 2009, and from a call for evidence to carers during this consultation on the strategy refresh.

We are also a key partner in Carers Week and the results from surveys undertaken for Carers Week are relevant in identifying what the priorities are for carers.

Please note: our numbered outline of priorities for carers is not in order of importance. All have equal priority.

³ NHS Information Centre, Survey of Carers in Households in England 2009-2010, Provisional Results (2010)

Respect for carers and access to integrated services

- Recognition of carers as expert partners in the care of someone with Parkinson's.
- Treatment as partners in service development, represented in the new structures to achieve accountability of health and social care and through new commissioning outcomes for Parkinson's services.
- An integrated and timely assessment of their health and social care and other needs, and a designated contact person, wherever they live.
- Sufficient resources to be allocated to, and spent on, achieving more choice and control for carers.
- Protection and expansion of social care services: cuts to social care will directly impact on carers.

Carers able to have a life of their own including access to respite

- A national funding commitment to continue investment in carers services, specifically the continuation of the carers grant
- Effective monitoring of national monies to ensure it reaches carers.
- Publication of the Strategic Health Authorities audit of PCT's delivery of carers funding and respite breaks
- Carers as a priority in new NHS policy frameworks.
- Research on the cost saving impact of carer support in health and social care.
- Improving quality and choice of care for people with Parkinson's
- Investment in emergency replacement care should a carer fall ill

Supporting carers financially

- Ensuring there is reform of the Carers Allowance
- Better information and advice for carers on benefits
- Raised awareness of the right for carers to request flexible working
- The government's welfare reform plans to contain an impact assessment on the effect on carers
- Protecting carers from the effect of social care cuts and potential increased charges for social care

Supporting carers to stay well

- Training for GPs in addressing carers health needs
- Piloting projects to provide replacement care to allow carers to attend medical appointments
- Improving access to aids and adaptations for people with Parkinson's
- Utilising new public health structures and funding to help deliver better health outcomes for carers and a reinvigorated training programme.

Protecting children and young people from inappropriate caring

- More research on numbers of carers under 18
- Investment in school support for young carers
- Multi agency guidance to ensure young carers are not inhibited from coming forward with their concerns

Views on priorities	Supporting evidence (including value for money)
<p><u>Outcome of 2008 Carers Strategy</u>: “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.”</p>	
<p>Priorities</p> <p>1. Recognition of carers as partners in care and experts on Parkinson's is essential. Parkinson's is a condition which is long-term, fluctuating and presents itself in ways which are very personal to the individual. The carer will have an insight that will be of value to professionals, particularly when someone is being cared for in hospital or residential care where medication management is extremely important to help someone manage their condition and not deteriorate.</p> <p>2. Carers also wish to be treated as a partner in the commissioning, quality assurance and development of services by appropriate involvement. The decommissioning or withdrawal of funding for carers centres, although these are user led and provide hard evidence of their value for money, is a particular concern. Similarly there are concerns about the quality of local services as new structures such as the Care Quality Commission, NHS Commissioning Board establish new roles, and the Audit Commission is scrapped. This leaves a hiatus in how local services are performing: quality ratings will “age” as a new ratings system for social care services is developed, leaving people using services with old information to rely upon.</p> <p>A priority is to ensure that carers are represented in the new systems to achieve accountability of health and social care services: the proposed national and local Healthwatch and in local Health and Wellbeing Boards. There must be effective scrutiny of local services and commissioners,</p>	<p>Evidence:</p> <p>1. The aim of our “Get it on Time” campaign is to ensure that people with Parkinson’s get their medication on time in hospitals and in the community, and we are training health and social care professionals on the importance of this. If people with Parkinson’s do not get their medication on time, their ability to manage their symptoms may be lost, for example they may suddenly not be able to move, get out of bed or walk down a corridor. Carers often report that the information they have provided to staff has been ignored, or they have not been asked or involved in care planning for their loved one. This is despite the knowledge that the carer brings about that person’s particular needs.</p> <p>2. Very few carers receive information through official sources: in our survey only fifth of carers (20%) had received information about health or social care services available, although 88% regarded it as important or very important.</p> <p>Although our survey found 55% of carers were already getting expert advice on Parkinson’s, this is still not enough. We know that occupational therapists, speech therapists, physiotherapists and continence advisors are essential in helping carers, as well as the person with Parkinson’s manage their condition. These are the preventative services that can slow decline into more critical needs. In our survey we found that access to these services was particularly patchy: almost half of people had never been seen by a physiotherapist, and two thirds had not been seen by a speech and language therapist or occupational therapist. There were also long waits for aids and adaptations.</p> <p>The Parkinson’s Nurse role is hugely valued by patients and their carers, and also provides exceptional value for money to health and social care services. In Stockport evaluations show savings in reduced hospital admissions and to the wider</p>

and robust inspection regimes of providers to ensure people are able to access safe services.

Implementation of the Quality requirement 10 of the National Service Framework (NSF) for long term conditions has been patchy. Whatever new policy tool replaces the NSF, it needs to be something that is robust, evidence based and addresses the major inequalities accessing the full range of services for people with Parkinson's. A key recommendation of the inquiry was for government to work with patient groups to develop a blueprint for Parkinson's disease services for commissioners and service planners. We would be delighted to work with government on commissioning for better outcomes for people with Parkinson's.

3. The more immediate priority remains for carers to be informed about their rights and that an assessment must be more than a paper exercise: delivering timely and appropriate support for carers as an outcome. Many carers feel the assessment has become an end in itself and find the experience demoralising. Carers should have an integrated and timely assessment of their health and social care and other needs, as well as the support they need in their caring role, together with a designated contact person, wherever they live.

In our view the social care assessment should routinely record the amounts of caring provided to illustrate what the service package would have been if no informal care was being provided. This could concentrate minds on why support for the carer is cost-effective compared to the costs of replacement care. Each social service department would be able to cost up what carers on their "books" alone save local council taxpayers.

health economy in the order of £50,000 a year. Across the country this type of saving could extrapolate to over £7.5 million a year. Yet the inquiry found that many areas did not have any or sufficient coverage of this service.

The inquiry found that commissioners need to urgently address these sorts of variations.

3. Our survey found that seven out of ten carers did not know that they were entitled to a local authority social services assessment. The numbers of carers receiving assessments remains low and the number of carers receiving services as a result of the assessment even lower. The inquiry questioned the cost efficacy of this approach, as well as pinpointing the major inequalities in access to services depending on where the carer lives.

Many carers rely on information from Parkinson's UK. In the last two years we have significantly expanded our Information and Support Worker (ISW) roles in order to cover every area of the country. This is having positive benefits to both people with Parkinson's and their carers through the one-to-one service, information and advice on Parkinson's and local health and social care services, as well as help with benefits and accessing other forms of financial support. In the last year alone ISW's have helped nearly 4000 carers.

Our branches and regional teams also identify what support may be needed for carers and many run discrete projects and days to help carers access anything from emotional support to social activities. For example in East Berkshire, we are running six sessions in 2010 for carers of people with Parkinson's, which cover the condition and medication, caring for the carer, coping with

<p>4. A major priority is for sufficient resources to be allocated to, and spent on, meeting the needs of carers to have genuine choice and control. This includes personal budgets and direct payments for the carer as well as for the recipient of social care services. When the system works well, and the carer has the right support and advice to administer a budget or delegate that role, they have reported that they are able to create a package of care that is flexible and personal to their situation, and releases them from the stresses of having to "fit" into the package of care on offer through social services.</p> <p>5. A further priority is to ensure that social care services are protected and expanded, and integrated with health where this will clearly deliver better services. A cut to social care services is a cut to carers support. With the raising of eligibility criteria for care or charges for care, if a carer can no longer access services for their loved ones, they will increasingly bear the brunt in terms of their health and finances. A major priority is to ensure there is <u>expansion</u> of day care, rather than a reduction in these services. And as we have demonstrated with our work costing up the impact of Parkinson's Nurse services, substantial savings can be made if the NHS invests in interventions that generate savings across the whole system.</p>	<p>psychological needs, looking after your back, looking after yourself and relaxation. These have attracted nearly two dozen carers to each session and they have been planned to suit carer commitments.</p> <p>4. Parkinson's UK is undertaking a project on choice and personalisation to see how our services can help people with Parkinson's and their carers make the most of new ways of exercising choice and control. We note that Carers UK's research⁴ has highlighted how the success of direct payments is heavily reliant on local authorities and their ability to support carers. Indeed, local councils can 'make or break' direct payments, according to the charity. The amount of paperwork involved can be highly off-putting for carers and more than three quarters of those councils surveyed (79%) have no contingency plans in place should something go wrong. In addition, in some areas there simply aren't suitable services available for carers to purchase with direct payments.</p> <p>5. Please see evidence under bullet point 2. We note the recent survey by Community Care magazine⁵ that eight in 10 councils in England will not meet adult service users' moderate care needs by next year on current trends. Three-quarters of councils now meet critical or substantial care needs only. But this will rise to 80% by next year under plans to tighten thresholds by councils currently supporting people's moderate care needs. This represents a sharp decline in provision from 2006, when 53% of councils supported moderate needs. This supplements alarming patterns such as closures of services such as day centres and increased care charges being made which are being reported on a daily basis.</p>
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⁴ Carers UK. Choice or Chore? Carers experiences of direct payments (2009)

⁵ Community Care magazine. Councils to deny support to all but the most needy. 15 September 2010.

Outcome of 2008 Carers Strategy: “Carers will be able to have a life of their own alongside their caring role.”

Priorities:

1. To ensure that there is a national funding commitment to continue the work of the Carers Strategy. This includes no cuts to the Carers Grant distributed to local authorities.

2. National monies must be effectively monitored and accounted for. We call on the government to ensure that the Carers Grant is not pooled into local authority general formula grant and that it remains identifiable within their budgets, and is subject to clear guidance and monitoring. The Care Quality Commission must continue to scrutinise performance on carers services.

3. To ensure local health services commit to fund planned breaks for carers. On 11 December 2009 we wrote to the Secretary of State for Health, as part of a coalition of charities with a shared concern that funding commitments from the Department of Health were not being effectively delivered by PCTs to deliver the Carers Strategy.

It is now a matter of urgency that the government publish the results of the audit which the Department of Health asked Strategic Health Authorities to undertake with PCTs. This should reveal how much of the second tranche of money for 2010-11 has been directed to carer’s services.

4. With eight years remaining of the current strategy, it is crucial that the government identifies ways in which carers are brought further up the agenda within the NHS. Services for carers should feature prominently in the proposed new outcomes framework for the NHS and NICE quality standards.

Evidence:

1, 2, 3 and 4. In our survey, 82% of carers regarded getting a few hours break as important or very important. However just over half were actually receiving some form of break. Further evidence is supplied by the survey undertaken for Carers Week 2010, which found that three-quarters (76%) of people looking after an ill, frail or disabled loved one do not have a life outside of their caring role. The majority of those surveyed can no longer rely on relatives for support either, as these relationships have suffered as a result of caring- 75% say they have lost touch with family and friends.

These statistics demonstrate how important it is to invest in carers services and ensure people get proper support.

Research published by the Princess Royal Trust for Carers and Crossroads Care found that only £10m of the first tranche of £50m for the Carers Strategy was being used by PCTs to increase support services for carers including respite. PCTs complained of a lack of guidance from Government. Many could not provide any information about whether the money, which went into their baseline allocations, was being spent on carers services or not. Further analysis estimates that only 26% of the remaining £100m for 2010-2011 will be spent on carers.⁷

Clearly this is not delivering value for money for carers and is evidence of what happens when monies for carers are not properly monitored, accounted for, or prioritised.

The lack of prominence in the current NHS Operating Framework (as an optional “Tier 3” performance indicator) was in part why PCTs have failed to deliver on the Carers Strategy grant.

⁶ Commission for Social Care Inspection, The State of Social Care in England, 2006-7 (2008).

⁷ The Princess Royal Trust for Carers and Crossroads Care, Tough breaks for carers (2010)

5. There is also an urgent need to widen research on the impact of carer support on residential care admission, hospital admissions and hospital discharges, to provide the hard evidence on why reducing carers support will be a false economy.

6. A major priority is improve the quality and choice of respite care in many areas as it continues to be a major barrier for carers in accessing support It is estimated that £1 in every £8 of adult social care is spent on assessment and care management.⁶ The government should consider ways into release more money into frontline respite services and avoid duplicating assessments: access to a flexible short break should not necessarily mean carers having to endure a carers assessment and a financial assessment, all of which can penalise middle income carers. All carers should be entitled to some free respite support, regardless of income.

7. A final priority is that carers need to be "allowed" to be ill: for many emergency planning has been identified as the priority area for them and a source of longstanding concern as to what happens to their loved one should they unexpectedly be unable to care.

5. Research has found that having a co-resident carer has a protective effective when it comes to residential care admissions, and when there is no carer, the person receiving care is more likely to be admitted into residential care. Carer stress is also a common reason in admission to nursing or residential care (38% of cases) and family breakdown - including loss of the carer - the reason in a further 8%.⁸

With the residential care cost for an older person averaging at £25,896 a year, compared to £7,540 a year for homecare⁹ local authorities and the NHS stand to gain much greater value for money by reducing admissions to residential care and hospital through proper carer support.

6. Lack of knowledge about Parkinson's disease amongst care home staff, particularly in medication management essential for Parkinson's, results in both people with Parkinson's and their carers unwilling to use residential respite. Many carers will say that respite care has to be appropriate to their situation: not everyone wants to use residential options or consider that they lack stimulation for their loved one, while many find homecare services inflexible in terms of meeting their requirements for respite.

7. 91% of those surveyed in our survey thought it important to have emergency backup help if they are unwell, but only 16% were receiving this. This causes enormous stress and pressure if the carer feels they cannot fall ill.

⁸ Princess Royal Trust for Carers and ADASS, Supporting Carers – Early Intervention and Better Outcomes, (2010)

⁹ NHS Information Centre, Personal Social Services Expenditure and Unit Costs England, 2008-9 (2010)

Outcome of 2008 Carers Strategy: “Carers will be supported so that they are not forced into financial hardship by their caring role.”

NB. In this exercise, we are particularly interested in support other than cash benefits.

Priorities:

1. The main priority for carers is ensuring that there is an adequate level of financial support, including an increase in the level of Carers Allowance and that the overlapping benefit rule that prevents those in receipt of a pension from receiving Carers Allowance is addressed. Raising the earnings limit for Carers Allowance, which prevents many carers from returning to work, is also essential.

2. It is also vital that carers receive better information and advice about the benefits available from the DWP, Jobcentre Plus and other government agencies.

3. Ensuring that carers can perform a working role if they wish to remain in work, or return to work is also a major priority, as well as raising awareness of their right to request flexible working and employers awareness of the benefits in supporting carers in their workforce

4. We have concerns about the true cross-governmental nature of the strategy if the proposals by the Treasury to cut the welfare bill are put in place without due impact assessment of the effect on the carers. This is a major priority and must be addressed by the cross government board on the Carers Strategy, and the Standing Commission on Carers.

Evidence:

1. Our survey found that nearly 30% of carers of people with Parkinson’s were financially worse off since becoming a carer. This figure is much higher for those who gave up work because of their caring role, or started caring when they were under 65. In our survey we also found that 14% of carers of people with Parkinson’s have had to leave work, and 8% of carers have had to reduce work since starting their caring role. Only 17% of carers were in receipt of Carer’s Allowance, including 21% of those under 65.

2 and 3. Only a fifth of carers in our survey had received expert advice about benefits or money matters, even though 77% regarded this as “important” or “very important”. Our evidence is complemented by the National Audit Office report¹⁰ which found a fifth of carers found it difficult to apply for Carers Allowance. It found only one third of Jobcentre Plus personal advisors believed carers they get the support they might need to combine caring and paid employment.

4. There are already direct consequences of cuts to the welfare budget to carers. For example, the decision in June’s emergency budget to uprate benefits by Consumer Price Index rather than Retail Price Index from April 2011 will lead to an annual loss of income for carers – as much as £135 by 2015-16 for those on Carers Allowance.

There are further financial consequences for the carer if the “cared for” person is in receipt of Disability Living Allowance, or Incapacity Benefit and its replacement, Employment and Support Allowance. This is due to the decision to only

¹⁰ National Audit Office, Supporting Carers to Care (2009)

<p>5. A further priority is to ensure that social care services are protected so that carers are not finding themselves in the position of having to self-fund, meet charges, or “top up” in order to ensure their loved one receives the care they need.</p>	<p>increase these benefits by Consumer Price Index rather than the Retail Price Index in the emergency budget. Coupled with the programme of medical testing for Employment and Support Allowance, which is not fit for purpose for people with Parkinson's, and the prospect of a further "medical test" for Disability Living Allowance from 2013 for all existing claimants of working age, people with Parkinson's and their carers are highly anxious about their future financial support. It should be noted applications for Carers Allowance only possible if the person being cared for is in receipt of the higher rates of Disability Living Allowance, so action to reduce access to it, may also reduce access to Carers Allowance.</p> <p>5. As noted in our earlier evidence, we are extremely concerned by the emerging pattern of councils raising eligibility for care services or making increased charges for services such as homecare or daycare. This puts extra caring and financial pressure on carers who may not have the means to meet these increased costs.</p>
<p><u>Outcome of 2008 Carers Strategy:</u> “Carers will be supported to stay mentally and physically well and treated with dignity.”</p>	
<p>Priorities:</p> <p>1. Carers own health needs should be addressed during the social services assessment process. The NHS should also have targets for increasing the number of carers registered with their GP, receiving annual health checks and flu jabs. Recognition by GPs should significantly improve the numbers of carers getting support: we look forward to hearing more detail of the Government’s plans to roll out a programme of training for GPs.¹¹</p>	<p>Evidence:</p> <p>1. Over half (51%) of our survey respondents reported that their health was worse as a result of caring. There is also deterioration in health the longer the person has been caring: 63% of those caring for ten years or more reported that their health was worse.</p> <p>Only 25% of carers of people with Parkinson’s were registered with their GP as a carer. Early identification of someone as a carer can help them avoid physical or mental health problems. The evidence shows that dedicated support workers based at the practice can have a dramatic effect in getting GPs to identify carers and significantly reduce distress amongst the carers.</p>

¹¹ Hansard, Column 295WH, 1 July 2010

<p>2. We encourage the government to explore the possibility of providing replacement care to allow carers to attend hospital appointments, screening services and health promotion programmes.</p> <p>3. A further priority is improving access to aids and adaptations, and the long waiting lists for these. The impact of these waits often falls upon the carer, in some cases causing health problems (particularly back problems) as the proper adaptations had not been put in place following hospital discharge.</p> <p>4. We believe the establishment of a new public health service, with ringfenced funding, offers an excellent opportunity for additional investment in carer's health outcomes. This, in addition, with the monies from the Caring with Confidence programme, could be reinvested in an ongoing training programme for carers that looks at key aspects which will help them keep healthy and well throughout the very different stages of caring for someone with Parkinson's disease.</p>	<p>2. 91% of those surveyed in our survey thought it important to have emergency backup help if they are unwell, but only 16% were receiving this. Carers feel they are not "allowed" to be unwell, or use what is respite time to attend appointments. This is not a true "break" for the carer.</p> <p>3. Our survey found more than one in ten (11%) respondents felt that their home was not suitable for them, 7% reported that stairs or steps were a problem and 4% were needing other adaptations. The survey also found that many people with Parkinson's are purchasing their own equipment, and many of these were doing so without advice. For example, of the 41% of respondents who had purchased bathroom aids, over half had done so without professional advice.</p> <p>4. Parkinson's UK and the Edmund J Safra Foundation are funding a research project at King's College London over the coming months in the South London and East Kent area. This will bring carers together in groups with a local Parkinson's nurse to learn new ways to cope with the challenges of living with and looking after a person with Parkinson's. The aim is to reduce carer stress and reduce the amount it affects carer's own health and wellbeing. We are hoping the project will be able to demonstrate the cost effectiveness of such initiatives as well as improving outcomes for carers health and wellbeing. If so, wider funding to expand similar projects would be welcomed.</p>
<p><u>Outcome of 2008 Carers Strategy:</u> "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."</p>	
<p>Priorities:</p> <p>1. There needs to be more research on the precise numbers of children and young people undertaking caring responsibilities. The first survey of carer's experiences who are in contact with social services (National user experience survey of adult carers in</p>	<p>Evidence:</p> <p>1, 2 and 3. Because Parkinson's is most common in older people, carers are frequently also older. However, an estimated one in twenty of people with Parkinson's are diagnosed before the age of forty, and one in seven diagnosed before the age of fifty. People with Parkinson's with young families worry</p>

England, NHS Information Centre (2010)) should be expanded to include experiences of children.

2. Schools are young people's natural communities and their role is vital in ensuring young carers health and emotional wellbeing. Encouraging schools to offer support and remove barriers they may face in education and training opportunities remains a priority.

3. It is vital that all agencies involved in supporting young carers, do so sensitively, confidentially and with a focus on the outcomes the young carer wants.

about the impact that living their condition has on their children, some of whom may experience a caring role because of the way the condition presents itself. Often it is the "non-motor" impact that children find hardest to deal with: the fatigue or mental health changes, such as depression, that their parent experiences.

We produce a number of resources for children to help them come to terms with what living with Parkinson's means for them and their loved ones. There are three resources aimed at 3-7 year olds, 7-10 year olds and 11-17 years. PD Kids also. We also run a Young Person's Network for younger people with Parkinson's.

The stigma surrounding illness and caring can often discourage young carers from coming forward for the help they may need. Many young carers fear that child protection or safeguarding systems will be invoked if they admit to undertaking an intense or inappropriate caring role. They also fear that their status may expose them to bullying.