

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*¹ – 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 Carers² believe that the vision in the Carers Strategy holds good. As part of the process for informing the Spending Review³, 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.

¹ Available to download at:

http://collections.europarchive.org/tna/20100509080731/http://dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

² The Standing Commission on Carers is an independent advisory body, providing expert advice to Ministers and the Carers Strategy Cross-Government Programme Board on progress in delivering the strategic vision of the national Carers Strategy.

³ For more information about the Spending Review see http://www.hm-reasury.gov.uk/press_10_10.htm

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 Agreement⁴ 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

⁴ Available to download at www.cabinetoffice.gov.uk/media/409088/pfg_coalition.pdf

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 Afya 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
Maidstone and Malling Carers Project Barbara Hagan [1,545 carers registered]	Address: 39-48 Marsham Street Maidstone Community Support Centre Maidstone Kent ME14 1HH Tel. no.:01622 685276 Email: barbara.hagan@vam-online.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 (please delete as appropriate)

- 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)

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 style="text-align: right;"><i>Quotes from carers in blue italics</i></p>	
<p>The recognition of carers’ contribution to society is vital and should be integral to all welfare, health, and social care policy development and service delivery.</p> <p>Carers issues should not be seen in isolation and as such all forthcoming proposed changes to Welfare Benefits, NHS and Social Care need to be assessed for impact on carers lives.</p>	<p>E.g. loss of DLA will not only negatively impact family income [reducing also means tested benefit premiums] but also remove carers’ eligibility to Carers Allowance</p> <p>The White Paper proposals re GP commissioning raises concern about likely NHS support for carers. Whilst undoubtedly most carers will turn in the first instance to their GP Practice for information and support, the majority are disappointed by the response. We find that even basic awareness as to ‘who is a carer’ often sadly lacking. It is therefore very unlikely that GPs will see commissioning support for carers as a priority.</p> <p><i>[We are currently hosting a DOH funded NHS Demonstrator Site Pilot which has a Carer Support Worker aligned to a designated GP Practice and another aligned to Hospital settings. This Pilot has shown the potential for improving awareness and support for carers in these settings. Much more work needs to be done to develop further good practice and to roll out across the sector before there can be confidence in carers needs being acknowledged and met]</i></p> <p><i>‘I have been struggling for years looking after my son – I didn’t even realize I was a carer, I was a mum. Since my first contact with the Carers Project I have learnt so much useful information, got practical assistance and</i></p>

Views on priorities	Supporting evidence (including value for money)
<p>Until such times as carers needs are fully taken account of and addressed across all departments and services, the provision of, and access to, dedicated carer services remains paramount. Carers Orgs/Centres sited within the Voluntary Sector provide a single point of contact for all carers. These services receive funding via charitable trusts and donations but largely rely on funding from their Local Authority via the Carers Grant. With the LA budget cuts Voluntary Sector funding is under threat. The continuation of the Carers Grant is vital and also needs to be ring fenced.</p> <p>In order for carers to receive the support they need and to make informed choices they need to be able to access advice, information and guidance that meet their specific needs and circumstances. They need a national point of contact [e.g. Carers Direct] which will address generic issues, answer specific questions and signpost them to local support. They also need a single point of contact at a locality level which will be able to provide comprehensive signposting to the whole range of local support and services. If the local Carer Support Organization provides this service they can also use the contact to identify other needs the carer may have and offer assistance with them. This is important as carers have often noted you can't ask for information or assistance with something you are not aware of in the first place. E.g. you may be anxious about leaving the person you care for alone but if you don't know that there is a local Carers Emergency Card Scheme you will not ask about this service. Sometimes carers need some assistance to understand and use the information they have been given to their best advantage. For example we may</p>	<p><i>services to help my son become more independent, made new friends and perhaps most of all now know where to turn as and when problems arise'</i></p> <p>The need to ring fence the Carers Grant is evidenced by the failure of the NHS to correctly allocate the £150 million given to Primary Care Trust to fund carers breaks. In West Kent [and I believe other areas throughout the country] this money went straight into baseline budgets and was spent on other priorities.</p> <p><u>Example of good practice</u> In 1996 after receiving constant feedback from carers around their difficulties in obtaining timely and appropriate information we decided to undertake some research into the information needs of carers. This was qualitative research completed by a group of carers who volunteered their time over a period of several months and facilitated by Maidstone and Malling Carers Project. A report was written and carers supported by MMCP gave presentations to representatives of all relevant bodies [Health, Social Services, Education, Benefits Agency and Vol Orgs]. One key finding was that information giving was inconsistent both within and between agencies and that even when given good information it was only about the agency that had been approached. This led to a key recommendation that agencies should pool budgets and produce signposting information that was 'client' specific and not 'service' specific. E.g. bringing together all information relevant for people caring for some one over 65 in one booklet.</p> <p>Although the research was well received action was not forthcoming. MMCP then decided to produce the information carers were asking for themselves. Again with another group of volunteer carers decisions were made around format, wording and content. Funding from charitable grants was then sought to research and print a range of 5 different booklets for carers living in the Maidstone and Malling area.</p>

Views on priorities	Supporting evidence (including value for money)
<p>give them information about their entitlement to a Carers' Assessment but in order to understand why this might be helpful and to prepare for an assessment they may need the opportunity to talk through their caring role and identify their own needs which they may have dismissed or minimized.</p>	<p>These booklets have been regularly updated and reprinted since 1996. Copies are sent to all of the 1,554 carers registered with us and also distributed widely throughout the local community [9,000 copies printed]. They have always received overwhelming praise from carers and professionals alike. [Cost is £5,000]</p> <p>The booklets are also available to download from our website www.vam-online.org.uk/carersproject.asp</p> <p>The following 2 comments are typical of the feedback we receive; A Carer <i>'Really is the most useful booklet I have ever been given – at last someone has taken the trouble to find out what we need to know'</i> An Occupational Therapist <i>'I use it all the time and carry it around in my diary on visits and if any questions come up I'm unsure of it will invariably hold the answer'</i></p>

Views on priorities	Supporting evidence (including value for money)
<p><u>Outcome of 2008 Carers Strategy:</u> "Carers will be able to have a life of their own alongside their caring role."</p>	
<p>Without doubt the top priority for this outcome is access to appropriate, flexible short breaks [formerly known as respite care]</p> <p>It is important to carers that any alternative care services meet the needs of the person they care for and that taking a short break is beneficial for both parties.</p> <p>Some people will need a regular break others occasional, some a few hours others for a few weeks, some may need overnight breaks. Planned breaks are needed to enable a carer to plan ahead but also rapid access for emergencies or times of crisis are also needed. Therefore flexible services determined by individual need are crucial.</p> <p>Taking a break is vital. However we have contact with carers who have become isolated and their social networks have diminished due to their caring role. This impacts on their self esteem and when presented with the opportunity for a short break lack of confidence is a barrier to joining existing activities in the community. Whilst joining a carer support group may offer a supportive environment in which to meet others, this does not appeal to all. Many need to spend the limited time they have away from their caring role doing something for themselves which is enjoyable, relaxing or stimulating rather than focussing on their role as a carer.</p>	<p>Without access to short breaks carers [especially those caring more than 50 hrs a week] carers will have little or no opportunity to have a life of their own. This increases greater social isolation, higher levels of stress, and the potential deterioration of the relationship between the carer and the person they care for. This in turn leads to ill health and increase to risk of breakdown of caring situation. This will result in greater demands on services, hospital admissions and need for permanent residential/nursing home care.</p> <p><i>'Just knowing I will be having a break gives me something to look forward to and keeps me going. Don't get me wrong I know I will be just as pleased to return to caring but I return with boosted energy and we both have something fresh to talk about!'</i></p> <p><u>Example of good practice</u></p> <p>We have developed a range of activity groups for carers. These groups offer a supportive and welcoming environment for carers to meet with each other but the focus is not on caring. Often the focus will be health and well being, developing new, or discovering old skills and interests. Usually the groups are facilitated by carers themselves promoting self esteem and confidence. Groups are set up in response to carer interest, current groups are; weekly swim/gym, weekly line dancing and exercise group, monthly book group and monthly walking group. Art/craft groups run for set number of sessions as are pampering sessions. These are a mix of very low cost e.g. book group and walking group to some with a cost attached e.g. swim/gym group [reduced rates negotiated] Total annual cost [£4,000]. These sessions are free for carers and funded by donations and applications to small grants.</p> <p>Benefits for individuals taking part include;</p>

Views on priorities	Supporting evidence (including value for money)
	<ul style="list-style-type: none"> • A carer who joined the card making group now produces cards at home and supplements her Carers Allowance [within allowed threshold] from their sale • A member of the Book Group attended the Kent Cultural Summit to talk about what the group meant for her. Following this experience she has now undertaken training to deliver carer awareness sessions to professionals. Her attendance at the Summit also resulted in a 4 minute film being made about the group. This can be seen by going to the Carers Page of Kent County Council website and clicking on 'Books' • Recently a carer phoned us to say she had just been for a check up [has very high blood pressure] and the nurse asked her what she had done the day before. When she explained she had joined the carers walking group she was told to 'keep it up – it is doing you the world of good, your BP and stress levels have come right down.
<p><u>Outcome of 2008 Carers Strategy:</u> “Carers will be supported so that they are not forced into financial hardship by their caring role.”</p> <p><i>NB. In this exercise, we are particularly interested in support other than cash benefits.</i></p>	
<p>Although it is stated that Benefits are being looked at in a different exercise we feel it is necessary to state that improving carers incomes must remain a priority. As previously mentioned any changes to the Welfare Benefit system must be assessed for impact on carers and the outcome taken into account when decisions are made.</p>	<p>If not adequately supported financially, fewer carers will feel able to take on a caring role in the future – this will undoubtedly result in increased demand for health and social services. This will be demand for services to replace what carers would have been doing and also people who would have been supported by carers to maintain levels of independence requiring services sooner.</p>

Views on priorities	Supporting evidence (including value for money)
<p>If carers are to maintain juggling both paid employment and caring then support and care services will need to be flexible to accommodate the working day [like current childcare provision]</p> <p>JCP initiatives to assist carers back into work offer assistance with alternative care to undertake approved training etc. Enabling carers, of people who need constant care, to remain in, or return to work would require the cost of alternative care to be met; as the cost in most cases would be the same or greater than earnings. Possibly a voucher scheme?</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>As mentioned in previous outcome the Carers Grant needs to continue and to be ring fenced. The loss of the NHS funding for Carers Short Breaks evidenced that carers will lose out against competing priorities, as their goodwill and willingness to care is taken for granted. We know of many carers who put off health appointments of their own due to difficulties in leaving the person they care for. This includes; GP appointments, dental appointments, and even necessary operations. These are the sorts of situations which desperately needed to be addressed by the NHS provision of short breaks and were ignored.</p> <p>Access to emotional support is vital. Many carers feel isolated by their experience and need to be able to talk to someone in confidence about their feelings and concerns. A range of options need to be available including groups, one to one</p>	<p>An example of carers being unsupported is illustrated by a carer with a heart problem and arthritis;</p> <p><i>‘My consultant has told me I must go for a short walk each day. My husband has dementia and I can’t leave him on his own, not even for a short time. He is unable to walk out of doors so if I took him with me I would have to push him in a wheelchair and I’m not strong enough to do this’</i> [Carer with a heart problem and arthritis]</p> <p><i>‘Thank you for letting me off load. I can’t talk about this to my family as they are too involved and I worry that if I keep burdening friends they will get fed up with me. Just knowing you are there if I need to talk helps me carry on.’</i></p>

Views on priorities	Supporting evidence (including value for money)
<p>support; both face to face and over the phone.</p> <p>There is concern that the tightening of Local Authorities eligibility criteria will be extended to funding of services which should be universally available and readily accessible to all in need e.g. carers support services</p> <p><u>Additional comment</u> All of the above comments are informed by our direct work with carers. Established in 1993 the Project currently has 1554 carers registered. 58 carers directly inputted their views into this exercise via group meetings. It is also based on comments received from carers at Maidstone and Malling Carers Forum, which has a membership of 668 carers and recently celebrated its 50th meeting. Quotes used are taken from written feedback and evaluation exercises we have undertaken.</p>	<p>Carers already contribute the equivalent of a second National Health Service in economic terms. If they need, information, support, training etc in order to continue caring, this provision must surely be cost effective.</p>

Views on priorities	Supporting evidence (including value for money)
<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>We work with all carers except Young Carers and have therefore left input to this outcome to those best qualified to do so.</p>	

Views on priorities	Supporting evidence (including value for money)