

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
Genetic Alliance UK	Address: Unit 4D, Leroy House 436 Essex Road London, N1 3QP Tel. no.: 020 7704 3141 Email: nick@geneticalliance.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

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)

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>Carers’ access to support services depends upon good quality, easily accessible information which clearly advises them of their entitlements and the steps necessary to obtain them.</p> <p>Carers are busy and any time they have outside of the caring role is valuable and scarce. Providers of support services should create a flexible system for access to support services that takes account of this and which facilitates carers timely access to support as much as possible.</p> <p>In instances where support is provided by more than one institution/agency, support providers should work together to present a simple pathway to access support.</p>	<p><i>“You don’t know what you are entitled to, so how can you find out?”</i> Focus Group Participant – Family Route Map Project</p> <p>The report of our Family Route Map Project identified a number of problems regarding access to information about what support services are available to carers and which support services they are entitled to.</p> <p>Carers found it difficult to navigate the complicated system and that too few professionals were available to advise them of their entitlements and how to access them.</p> <p><i>“Everything I’ve found out... not just health, social stuff, everything, is from other mums!”</i> Focus Group Participant – Family Route Map Project¹</p> <p>1. www.geneticalliance.org.uk/projects/familyroutemap.htm</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>Genetic Alliance UK supports the aim to allow carers to have a life of their own alongside their caring role.</p> <p>To achieve this, providers of healthcare need to accept and support the role that carers provide to the healthcare of those with long-term conditions.</p> <p>Healthcare providers can assist carers by providing one-stop appointments at flexible times (such as evenings and weekends) to ensure that a work-life balance can be maintained by those that hold or seek employment.</p>	<p><i>“These very rare diseases’ make patients and their families particularly isolated and vulnerable.”</i></p> <p>Rare Diseases: Understanding this Public Health Priority. Eurordis, November 2005.</p> <p>A recent survey across Europe demonstrated that for 6 in 10 genetic disease cases at least one person in the household had to reduce his/her workload or stop working altogether. This was the case 100% of the time for single-parent families.²</p> <p>2. archive.eurordis.org/article.php3?id_article=1594</p>

Views on priorities	Supporting evidence (including value for money)
<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>The process of administration for benefit provision to carers needs to be simplified.</p> <p>Caring should be recognised as a role in society. This will provide dignity to those that adopt this role.</p> <p>Provision should be made for national insurance contributions and retirement benefits in line with those people in paid professions, to be provided for all carers.</p> <p>As we have stated in our answer to our previous question, for those that hold or seek employment, healthcare providers can assist carers by providing one-stop appointments at flexible times (such as evenings and weekends) to ensure that work is not disrupted.</p>	<p>In families where more than one child is affected by a rare genetic condition, carers find themselves duplicating information and applying separately for benefits to support each child’s care. They are unable to refer to the fact that they are caring for more than one child.</p> <p>The system does not take account of the demands on the family and impact of each child’s needs together with the ability of the family to care for more than one child.</p> <p><i>“The system needs tidying up.”</i> Focus Group Participant – Family Route Map Project¹</p> <p>1. www.geneticalliance.org.uk/projects/familyroutemap.htm</p>

Views on priorities	Supporting evidence (including value for money)
<p><u>Outcome of 2008 Carers Strategy</u>: “Carers will be supported to stay mentally and physically well and treated with dignity.”</p>	
<p>Genetic Alliance UK supports this aim. Additional support to maintain the health and wellbeing of carers will ease pressures on the NHS.</p> <p>It should be recognised that the psychosocial impact of a condition upon the patient can be passed directly to their carer.</p> <p>Practice Nurses and other healthcare professionals such as Health Visitors could act as ‘advocates’ signposting carers to information and support (continuing professional development could be the conduit to provide training for this).</p>	<p>Individuals with rare and/or complex genetic conditions lack the support of healthcare professionals with the understanding of the medical and psychosocial impact of that genetic condition on the family³.</p> <p>Some conditions affect people’s appearance which may lead to social stigma and in some instances bullying.</p> <p><i>“I really had the ‘mick’ taken out of me at school, I was bullied...just because I’m different.”</i> Focus Group Participant – Family Route Map Project¹</p> <p>Carers described a lack of psychological support and general lack of mechanisms for support. Practice Nurses were perceived as friendly and supportive and it was felt that with enhanced training they could offer a vital link at GP surgeries and practice-based clinics.</p> <p>1. www.geneticalliance.org.uk/projects/familyroutemap.htm 3. Marini, F et al. Orph J Rare Dis 2006; 1 Art 45</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>Carers should be given support to make informed decisions regarding educational choices for children in their care. This should be seen as a positive partnership between local authorities and all concerned.</p> <p>Building and optimising partnerships with parents and support groups is crucial to collaborative approaches towards improving teaching and learning.</p> <p>The problem of patchy access to free transport after the age of 16 should be recognised as a barrier to access to education and solved.</p>	<p><i>“We have had to take our lad [affected by Gorlin Syndrome] out of school. He’s 15 and he was in and out of hospital having the treatment and then there was the recovery period. He’s now doing GCSEs and because he got so far behind with the work there is no support at all. We had to fight our corner because they were actually going to prosecute us for him not being at school.”</i></p> <p>Focus Group Participant – Family Route Map Project</p> <p>Carers have described to us their ‘battles’ to find appropriate schools and education for their children, particularly as they moved up from Primary to Secondary education.</p> <p>Parents told us that for many, further education is not possible, as Sixth Form Colleges were often located some distance from their home and free transport is not available everywhere for disabled children after the age of 16.</p> <p>Not all children with complex genetic conditions are seen as eligible for a Statement of Special Educational Needs; symptoms and treatments can vary and change as the child develops, sometimes without a diagnosis ever being made.</p> <p>Education is of prime importance to these children whose parents often feel they will become disadvantaged adults.¹</p> <p>1. www.geneticalliance.org.uk/projects/familyroutemap.htm</p>